

**NARRATING EXPERIENCE: THE ADVANTAGE OF USING
MIXED EXPRESSIVE MEDIA TO BRING AUTISTIC VOICES TO
THE FORE IN DISCOURSE AROUND THEIR SUPPORT
REQUIREMENTS.**

by

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Abstract

This study explores methods of shifting the power imbalance within autism research by acknowledging the autistic voice as the expert 'insider'. This is critical, since statistics relating to access to services demonstrate social barriers to inclusion and a negative impact on wellbeing.

With communication as a central challenge between autistic and non-autistic individuals, I explore methods to access the views of autistic adults regarding their experiences, support requirements and provision of appropriate services. Therefore, my main research question concerns the deeper exploration of data informing an evaluation of a support service to understand how some autistic individuals conceptualise their experiences.

My research design, informed by autistic people, focused on context and power issues through method flexibility. I used collages and narrative diaries to gather written and visual data before presentation and analysis as three individual case studies and also as a meta analysis providing a broad picture of themes. My key contributions to autism research are: a framework blending IPA, narrative analysis and critical discourse analysis with distinct sites of analysis (narrative process, images of autism, audiencing, turning points and discourse); use of a flexible methodology, allowing the diverse communication preferences of autistic individuals to be valued and included; and the contextualisation of autistic narratives to

locate power, make sense of autistic individuals' experiences and determine of authenticity of voice.

My findings demonstrate how the 'outsider' location of power can negatively impact on the autistic agenda. To address this, autistic people need to be seen as the expert in their lives, and this study demonstrates how autistic and non-autistic individuals can work together in realising this goal.

Dedication

To my sons, Patrick and Isidro, you are both inspirational, and your encouragement throughout my study journey enabled me to realise its completion.

Patrick, your refusal at age 8 to write about an uninspiring picture for an exam showed me about the importance of quality and accessibility.

Isi, your use of dance to express yourself as you find this easier than words highlights the requirement for diversity and creativity.

Also, my brother, Steve, I dedicate this to you. Silence takes many forms, and for me, your silence is the loudest voice. Never give up.

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To my supervisors: Dr Karen Guldberg, thank you for helping me condense my thoughts; and Dr Jerry Tew, without your encouragement I would not have 'felt comfortable in my own skin', able to explore and express my identities.

Sarah Clemerson: you have the amazing gift of facilitating a process whereby I could work through extremely challenging moments and continue my studies. You were always there without fault. Sam Gamblin: your unerring confidence in me and focused attention to the support I required was invaluable.

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Chapter 1: Introduction

Context for this Research

In a climate where the recognition and diagnosis of autism and Asperger syndrome (AS) is on the increase (Howlin and Moore, 1997), it is argued that this apparent 'epidemic' in autism can be attributed to the 'broadening of diagnostic criteria', 'greater public awareness' and 'intentionally improved case findings' (Gernsbacher et al., 2005). Coupled with acknowledgement that autistic girls are not being diagnosed (Gould and Ashton-Smith, 2011) and manage their challenges differently (Moore, 2013), there is continued dissatisfaction at the way services fail to provide adequately. This is particularly heightened among those previously identified as 'having high-functioning autism' (Barnard et al., 2001). The current context is one where services do not engage adequately with autistic individuals (DoH, 2010a; b; HMSO, 2009; 2010).

The combination of autism-specific legislation with other legislation and policy, such as that set out by the Convention on the Rights of Persons with Disabilities (UN, 2006) and the Equality Act (HMSO, 2010), highlights an urgent need to redress the balance in relation to this issue. This is corroborated by research concerning education and good practice (Jones et al., 2008; Parsons et al., 2009). A failure to meet with and consult autistic people concerning their views, has resulted in many adults on the autism spectrum remaining in the family home as opposed to living more

independently (Howlin et al., 2004) facing barriers to accessing appropriate and relevant work (Howlin et al., 2005; Robertson, 2010b), or difficulties continuing into higher education (Beardon et al., 2009; Madriaga et al., 2006).

Motivation for this Study

The original approach I have adopted in my study is one of standpoint epistemology. This can be understood to be where a researcher has life experience of subordination or exclusion, and which places them in a better position [as a researcher] than that of people who are seen to be in positions of privilege or power (Tew et al., 2006). I bring to my research my experience bridging identities which disregard the imposed categorisations of neurotypical norms, and I have first-hand knowledge of the extreme levels of anxiety caused by sensory sensitivity and overload, which impact on my ability to function as I would wish. For this reason, my position as researcher and author emerged as a blend of 'curious outsider' combined with some 'insider lived experience'. Whilst my understanding of the support requirements of autistic individuals has emerged from an insider perspective in relation to service provision, a key element of my study relates to acknowledging the potentially different experiences of others and contributing to knowledge production at Autscope (Ridout, 2013b; 2014b)

From a young age, I have been concerned at how the agenda for listening to and acting on the distress faced by individuals with different challenges has been weighted in favour of listening to the non-autistic 'experts' (Brownlow et al., 2006). The 'experts' have included practitioners and researchers, but also parents and family who have often been 'informed' by the former of the 'correct terminology to use'. This situating of the expert as being the practitioner (outsider expertise) (Becker, 1963, p1) has inevitably shaped attitudes surrounding both autism and the wider field of disability. Ultimately, this has excluded autistic individuals from: informing debate around their support requirements; any aspect of the research process other than as 'object being observed'; meaningful involvement in the improvement of services (ARGH and HUG, 2011; Brook, 2014; Dunn, 2014b; Milton, 2011b). This situation is one which reflects the power imbalance that has accrued in the field of autism as a result of this 'outsider expertise' approach, and which has impacted directly on discourse with autistic people around the provision of services.

Insider knowledge and expertise, or placing autistic people as the experts in their lives, is the concern of my study. This focus acknowledges that communication is one of the central challenges experienced by autistic people, and I felt that this challenge frequently arises for reasons other than those explained by the more usually offered deficit, or medical, model of disability with a focus on dysfunction and blame. Reasons include, among others, opportunity and time to engage in debate

regarding support requirements and meaningful methods of exchanging information, especially concerning areas such as skills and interests. My view was that it was likely that research into this area was either failing to explore the true nature of communication challenges, or, if it was exploring them, that critical research findings were not impacting on policy and practice. Consequently, one of the initial aspects of my study sought to develop ways of explaining meaningful methods of communication between autistic people and service providers. This was a theme that I was passionate about since family and friends experienced continual difficulties in respect of equal access to services, and this contravened legislative mandates (HMSO, 2010).

A further concern that I had from the outset was that 'being autistic' was the sole identity privileged to autistic individuals if they were successful in accessing services. Rather than being able to account for their own identity, the experience was one of being labelled as 'a person with autism' or as being 'someone who has autism' with all the difficulties and problems that that label brought. Consequently, access to services was further limited. I decided that my study would listen to the narratives of autistic people as the experts in their experiences, whilst at the same time placing these in a wider social context. For this reason, I would therefore need to explore sites of meaning-making within narratives which would be open to discourse with non-autistic individuals/service providers.

Study Objective

My study aims to explore the methods of engaging with autistic adults to access their views on their support requirements and provision of appropriate services. The treatment of autistic people as individuals as opposed to a homogenous group (Milton and Bracher, 2013) is a central feature of this study, with the voice of autistic participants critical in informing the methods used for data collection.

My Approach

As stated, my approach is one of standpoint epistemology, meaning that I have experience of exclusion (Chapter 3.1), and my study takes the form of a bricolage of different media accessed by autistics to create a layered narrative of their individual experiences. This has also enabled me to tap into diverse theories, described below, in a manner that best enabled me to respond to my research questions. The funding of much of academia also includes a responsibility to inform policy and practice, yet I believe that the rigidity of academia itself, for example as seen in inflexible and inaccessible methodologies, often works against the interests of those on whose lives it impacts. For this reason, I have selected the tools that I felt facilitated a way forward in the debate on the provision of autism friendly services.

The framework I will be using for my study (Chapter 3.2), represented in the diagram below, shows how the theoretical and analytical frameworks

relate both to each other and to Oliver's (1990) view about the purpose of social theory, which I am using to underpin this study, namely to describe experience, to explain experience and to transform experience.

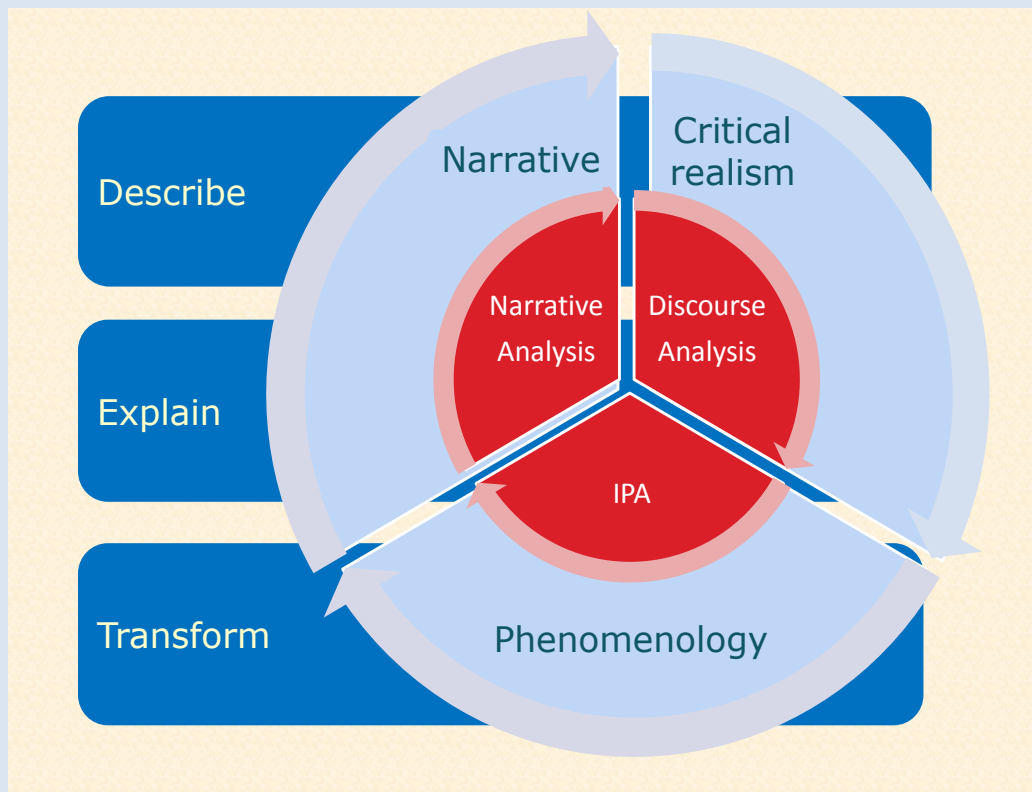


Figure 1: Summary of analytical framework

Interpretative phenomenology

The framing of autism is critical to my study and is informed by social injustices experienced personally and by family and friends (Milton and Moon, 2012; Milton and Ridout, 2014). My work differs from that of other research in that narratives and discourse around autism utilised seek to address the agenda set by autistic people themselves by focusing on and listening to their voice (Huws and Jones, 2008). The evidence I am seeking relates to how autistic individuals story their experiences, and the emphasis they place on certain aspects of these. In addition, I am

interested to know how autistic participants conceptualise their wellbeing, and how this impacts on their identities (Andrews, 2006; Dawson, 2006; Murray, 2006a; Sainsbury, 2009).

Narrative research

Narrative research has become increasingly popular in the social sciences, and the work of Molly Andrews has had a considerable impact on the way in which I ultimately chose to view my data. The notion of a master narrative against which [autistic] people story their lives and resist dominant cultural narratives (Andrews, 2002a; Benwell and Stokoe, 2012) fascinated me as it seemed to address the problem that I wished to explore, namely that the dominant narrative of autism from the 'expert outsider' perspective contradicted stories emerging from the insider perspective. Consequently, how autistic people fit their narratives to the master narrative becomes a major theme of my enquiry. Other influences on my study have been the work of Czarniawska (2004b), Luttrell (2003) and Riessman (2005), which spurred me on to consider using narrative methodology as a tool and to unravel narratives storied in a variety of forms using a layered approach. In addition, work by Phoenix (2008) and Georgakopoulou (2006) led me to consider the role a narrative plays, the plot being established (Riessman, 2003) and links being made between the 'now' and the 'then' by tapping into our imaginations (Andrews, 2014).

Research around narratives has frequently made use of the terms 'narrative' and 'story' as different entities, with the definition of the latter largely relating to a plot. For the purposes of this study, I use the terms interchangeably, as both nouns (a narrative, a story) and verbs (to narrate, to story) as I believe the notion of a plot (with a beginning, middle and an end) to be a defining feature of both, although the ending may not be a direct result of either of the former two elements.

Communication and discourse

Exploration of communication challenges experienced by autistic individuals is an integral part of this study. As such, I shift my focus from the use of language and conversation skills, delving into the themes of discourse, power relations and exclusion (Tew, 2006; Tew et al., 2006) and the relationship between narrative, discourse and identity construction (Benwell and Stokoe, 2012; May, 2004). That identity construction is both an individual and a social process is a critical argument that I pursue, since in the context of discourse and power relations the implication is that identities may be imposed (Ridout, 2013c). This has implications for the wellbeing of autistic individuals and is an aspect that I discuss in my data analysis.

Research paradigm

I present my work as an interpretative study, where I place emphasis on the contextualisation of the experiences of autistic individuals as I endeavour to understand their voicing of their social worlds.

Using a blend of the above mentioned forms of analyses, together with different sites of meaning making (process, image, audiencing, turning points and discourse), I explore the individual experiences of three autistic people using narrative data collated using two methods, a narrative diary and photomontage/collage. These were informed by autistic individuals for the purpose of informing my pilot study and evaluating a regional support service for autistic adults and teens 16-18, and feedback regarding the advantages and limitations of these shaped the method design for my main study. I then present the narratives as three separate case studies chosen as an example of how these methods were differently accessed according to communication preferences and opportunity. In addition, data from two mothers is included, the narrative text having been volunteered, and the draft collage data having emerged spontaneously. These serve to provide an example of similar and dissimilar agendas and terminology, but are not included in the final discussion as the focus of my study is the experiences of the autistic authors as told by them.

Approach summary

This combination enables me to place the autistic individual as the expert insider (IPA), narrating their experiences in a range of ways (visual and dialogic-performative) and with opportunity for discourse.

Research Questions

In order to achieve my objective, I explored the following research questions.

Meta question: How can data informing an evaluation of a support service be explored in greater depth in a research study to understand how some autistic individuals conceptualise their experiences?

1. How do mixed expressive media enable autistic adults to voice their feelings and thoughts about themselves and their future?
2. How do the narratives of autistic adults inform us about their identity and wellbeing?
3. In what context(s) are these narratives taking place, and how is power situated within this?

Answering my Questions

An exploration of narrative layers used is influential as my data is accessed by working across and within data sets. Additionally, the sites of

meaning-making that I draw on enabled me to find turning points, where the lives of individuals may be transformed as a result of being able to story their life to a willing audience, and particularly one which is able to act (or perceived as such) on their experiences.

Terminology

Throughout my study I use the term 'autistic' generically to refer to anybody on the autism spectrum and recognise that it is reclaimed and used by many to acknowledge differences positively. This is in contrast to 'a person with autism', since autism is an inherent part of the individual and as such cannot be separated from them (Sinclair, 1992). The term 'autism spectrum' is used to refer to anybody, with or without a diagnosis of autism, and also who may self-identify as autistic. A further term utilised throughout is 'neurodiversity', which I believe welcomes and embraces the wider differences and similarities experienced by the human species. In acknowledgement of those of us whose 'neurocognitive functioning diverges from dominant societal norms in multiple ways', I use the term 'neurodivergent' (Walker, 2014). Finally, use of the terminology 'autistic individuals' or 'autistic people' throughout this document will reflect the spectrum of differences/challenges faced by autistic people with a diagnosis, or who self-diagnose as being autistic, and that the term 'autism' describes their different way of processing information (Murray et al., 2005). In addition, I have, at times, used the

term 'author' to describe those crafting their experiences whether using text, diagrams, mind maps, lists, draft collages or collages.

Choice of terminology has been challenging for me due to the disempowering way it has been used with me, my family and friends, and this has proved to be an important strand informing my positionality. In addition, I was aware that many practitioners and researchers working in the field of autism continue to use terminology that is often not that which the autistic community as a whole find useful. Frequently, that used separates autistic people from autism, as opposed to seeing autism as an integral part of them and acknowledging the 'cornerstone issue' of diversity embedded in autistic autobiographies (Davidson and Henderson, 2010). Consequently, articulating the distressing impact of certain terminology and attitudes has been essential in developing my confidence as a researcher, so I considered alternatives that were more embracing of diversity.

Personal knowledge of communication differences experienced by autistic individuals has enabled me to focus on diverse communication strengths and preferences, and turn this to my advantage when exploring preferred terminology (Ridout, 2013a). Although, conversations with family, friends and colleagues have enabled me to select terminology that many autistic individuals consider to be more appropriate and ultimately more empowering, I am cognisant that choice of terminology is a personal matter. Indeed one of the challenges of my research design has been

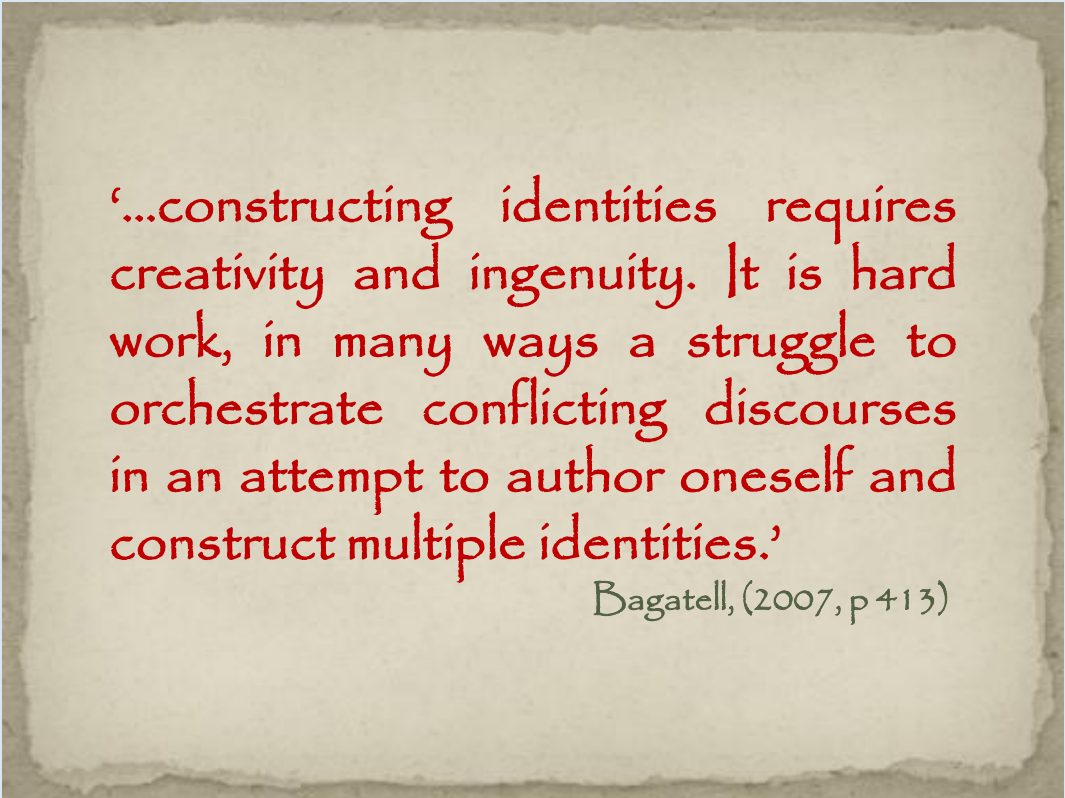
being able to acknowledge and include the differences and similarities in terminology used by autistic individuals, non-autistic individuals and society as a whole.

Breuer and Roth (2003) observe that knowledge and perspective are inseparable, since the former depends on the position of the 'knower'. Whilst this provides a useful perspective in explaining different terminology employed in relation to autism, it does not simplify the issue. Throughout my research journey, I have been frequently reminded that terminology will never be an area encompassing a unified approach to acceptable terms. Nevertheless, language has a key part to play in the enfranchisement of individuals or facilitating access to social or political debates, particularly those impacting directly on their lives (Pound and Hewitt, 2004).

The social construction of language and terminology means that they consequently shape our fit in society in terms of how we see ourselves, and portray how we are perceived by others (Searle, 1995). This area is often reflected by oral, written and visual narratives, and may portray positive or negative images. An example of this exploited by rappers in lyrics used to express strong viewpoints prompted the request from activists, involved in the political campaigning site Change.org, for an apology and removal of the lyrics: "I'm artistic, you niggas is autistic, retarded" (Heeley, 2013). In fact, there is frequently a backlash when activist groups reclaim terminology used to discriminate against them and

marginalise them as individuals/communities, and inevitably this offends some. However, the coupling of negative terminology as in the above example is provocative, as it stresses a hierarchy of embedded dysfunctions and a sense of homogeneity, which at best is unhelpful, and demonstrates the use and possible effect of antiquated terms. This coupling of terminology also impacts on identity, and is elaborated on in my literature review.

A further example of the socially constructed nature of language is provided by Warmington (2010), who observes that since the definition [of race] changes over time, it must be a social construct. This resonates in relation to autism, where individuals experience high levels of discrimination and disenfranchisement. This example also illustrates another point. Historically, discrimination and prejudice have easily progressed unchallenged, with the blend of negative labelling, language, access to public resources and power being used to manipulate, disenfranchise and dominate (van Dijk, 2008, ch.9). Today, with the advent and advance of social media, previously disenfranchised individuals are able to tackle this both collectively and individually, encouraging others to also take action, although as Bagatell (2007) observes below:

A quote is presented on a rectangular piece of aged, yellowish-brown paper with a deckled, torn edge. The paper is centered on a light blue background. The text is written in a red, serif font. The quote is: '...constructing identities requires creativity and ingenuity. It is hard work, in many ways a struggle to orchestrate conflicting discourses in an attempt to author oneself and construct multiple identities.'

‘...constructing identities requires creativity and ingenuity. It is hard work, in many ways a struggle to orchestrate conflicting discourses in an attempt to author oneself and construct multiple identities.’

Bagatell, (2007, p 413)

In a presentation at a Critical Autism Seminar, McGuire (2011) discussed how language frames autism, and argued that the presentation of autism by the media is as ‘a guilty deed, a criminal’ (seminar notes). This argument underlines the importance of choosing words carefully as they reflect my philosophical position. Language used has a direct effect on us, informing and shaping our individual and collective experiences. As an ever-changing mercurial entity, it shapes and guides research and inevitably moulds the epistemological, ontological and political assumptions underpinning my study. As a powerful tool in the formation and refinement of ideas, the interplay between personal experiences and language used in my study are influential in relation to discussion of potential areas of bias, and a motive for progressing this area of work.

The manner in which we communicate what we do is, therefore, as important as what we say and how it comes to be interpreted. The whole process of this engagement, either thinking or conversing with oneself or others, is rich in opportunities to see things from different perspectives. Taking this one step further, these new perspectives enable us to re-adopt an iterative approach to our engagement with others and check our understanding or communication of thoughts.

Finally, in the context of this study, and in recognition of the argument posed by Fairclough (2009) concerning power and language, the term 'service user' is reclaimed as a term under the social model of disability. This position pays respect to the importance of choice, right, differences and shared experiences of services which are historically associated with stigma, segregation and discrimination, poverty and oppression, exclusion, restricted quality of life (Beresford, 2005; Reeve, 2004).

Contribution of my Study to Autism Research

My approach, or bricolage, has allowed me to view the experiences of autistic individuals gained by adopting a flexible methodology which offered two adaptable methods. Working across a diversity of data sets, I have then analysed data to build a detailed, differently informed and arguably more accurate picture of autistic experiences. This has been achieved by presenting my data in the context of: the main themes emerging from the evaluation of a regional support service for autistic

adults; changing representations of autism as depicted by emerging theories; and the introduction of relevant legislation. By presenting my data in this context, I have been able to demonstrate how the gradual inclusion of the autistic voice facilitates the reshaping of the current representation of autism and presents an agenda which reflects their real life experiences. The importance of this critical and exciting development should not be undermined.

Readers of this study will be able to reflect on whether:

1. employing diverse methods enables autistic individuals to narrate their experiences meaningfully by allowing:
 - time to process information and thoughts and thereby reduce task-related anxiety;
 - space, which addresses issues of sensory and social overload and also serves to reduce task-related anxieties.
2. different layers of information provided by the elements of each approach facilitate the construction of a more robust data set;
3. use of diverse methods extend opportunity for a diversity of individuals to engage in discourse regarding support requirements;
4. the adoption of a flexible methodology is more inclusive of people who would otherwise not have a voice;
5. a new and positive alternative to current practice is offered by this approach.

Presentation

The presentation of my thesis includes slides, which have acted as a creative visual method to help me develop key thoughts, focus on core issues and handle data. Consequently, I decided to use these to enhance the presentation of my thesis. In so doing, I hoped that readers would find the visuals both interesting and useful, enhancing engagement in the narratives being told.

In the presentation of my data in Chapter 5.3., I have continued this presentation technique to summarise the themes each individual has raised as set against my research questions. I then extended this approach into Chapter 6, where I reviewed collective themes addressed.

Summary

The negative impact of inadequate service provision on autistic family and friends led me to begin my PhD journey. My concern about a failure to engage with or consult autistic people, and the reporting of the economic impact of autism more broadly using 'outsider expertise' resulted in me exploring a diversity of methods informed by autistic people to access their views on their support requirements. Placing the autistic voice at the centre of this study, I have endeavoured to unravel narratives of autism as told by autistic individuals. Where the narratives of participants'

parents or support workers were knitted into the autistic narrative, I have included these as I believe them to be an interesting layer to the story.

My thesis is divided into 8 chapters. In Chapter 2, I discuss constructions of autism and implications for people and services, and this is divided into 4 key areas: the autistic voice regarding involvement in service provision; policy and legislation; theories and models of disability informing this area; and key themes relating to my research questions, namely identity, context and power and wellbeing. I elaborate on my theoretical and analytical framework in Chapter 3 and discuss my methodology in Chapter 4. My individual case studies are discussed and the findings are presented in Chapter 5, and Chapter 6 is concerned with a meta analysis of my case study findings. Discussion of my findings is covered in Chapter 7, and finally, I draw conclusions and consider implications for possible future research in Chapter 8.

Chapter 2: Constructions of Autism and Implications for People and Services

Meta Theme

- The Autistic Voice regarding Involvement in Service Provision

Policy and Legislation setting my Study Context

Theoretical Background

- Theories of Autism
- Models of Disability
- Neurodiversity

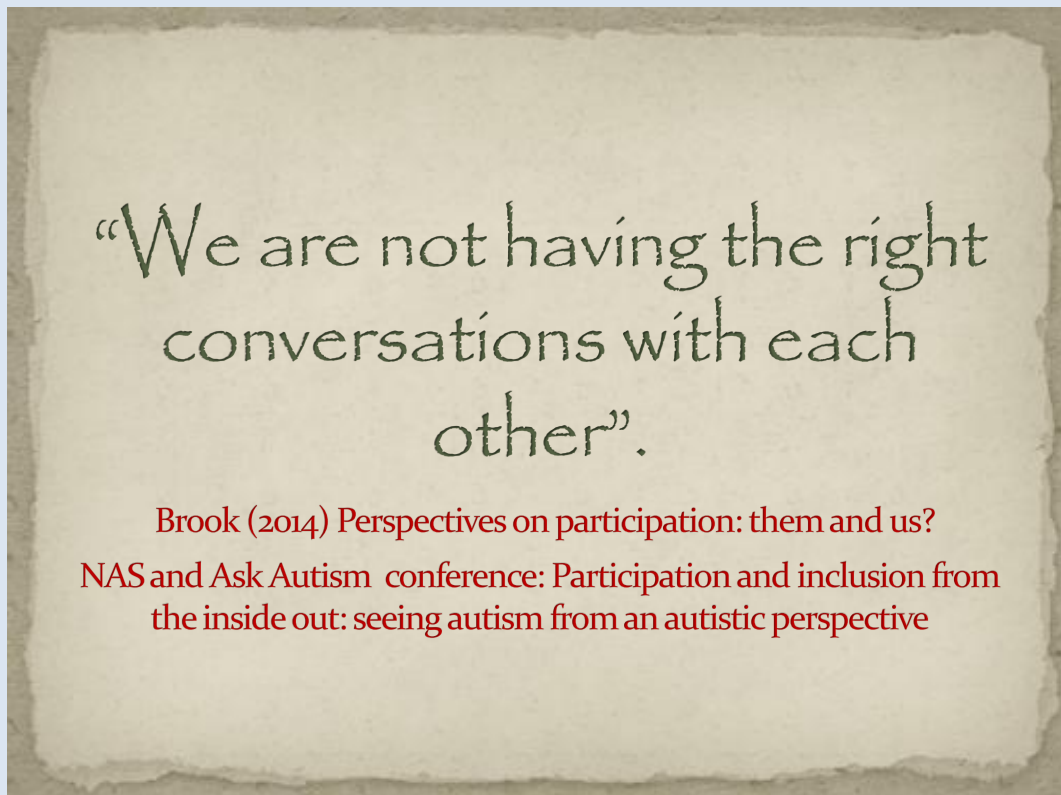
Key Themes Relating to my Research Questions

- Identity, context and power
- Wellbeing

Summary

This thesis concerns narratives and discourse around autism and seeks to address the agenda set by autistic people themselves. This chapter is divided into four main sections: the first section provides an overview of the autistic voice regarding involvement in service provision; secondly, I locate my work in the contextual background provided by legislation and policy; the third section provides an overview of some of the main cognitive theories of autism influencing my study, linking these with models of disability; the fourth section explores literature relating to key themes addressed by my research questions, namely identity, context and power, and wellbeing. I then summarise the literature and its implications before moving on to my methodology.

Section 1: Meta Theme: The Autistic Voice regarding Involvement in Service Provision



The above view reflects the concern held by many autistic individuals regarding services – a failure in meaningful conversation between non-autistic and autistic people. Given this scenario, it is easy to understand why services fail to address the requirements of autistic people, and it links with the idea that the voice of non-autistic others may take precedence, which is discussed later in this section. In fact, the autistic voice on service provision and support requirements reflects a diversity of views, particularly when the detail is under scrutiny. However, the broader perspective is more readily defined as follows:



Figure 2: Autistic voice on service provision (author's summary)

The voice of autistic people does not, currently, impact on services (ARGH, 2014; ARGH and HUG, 2011; Beardon et al., 2009; Beardon and Worton, 2011; Robertson, 2010b). On the contrary, a discrepancy exists between the priorities of autistic people and current investment of research funding in the UK (Pellicano et al., 2013). Furthermore, autistic people have not typically been involved in matters pertaining to them other than at participant level (Moon, 2014c; Parsons et al., 2009). This draws attention to the manner in which autistic people are subjected to scrutiny by researchers and practitioners (Milton and Moon, 2012), and there are concerns among autistic activists relating to knowledge production, involvement of autistic individuals and expertise (Arnold, 2014b; Brook, 2014; Graby, 2012; Milton, 2013). Moreover, in terms of

involving autistic individuals in service provision, and thus supporting them in their wellbeing, there is frequently an imbalance between what people say and what is heard (Milton and Bracher, 2013).

The emotional impact of autistic identities framed by non-autistic others, and its subsequent impact on service provision, is a concern both in the UK and abroad (McGuire, 2011). A tendency by services to use the medical model of disability, characterised by language of dysfunction and deficits, frequently leaves support requirements unmet, since autistic individuals find this provocative and inappropriate (Dunn, 2014a; Milton and Moon, 2012; Moon, 2014c; Ridout, 2014d; Simone, 2014). Furthermore, autistic people may make use of avoidance strategies to escape identities originating from and imposed by the language of outsiders (Baines, 2012). Language used is key to facilitating the development of a positive self-image and identity (ASAN, 2014; Autistic Hoya, 2015), so this unwillingness by many autistic people to engage with services is perhaps unsurprising.

An additional impact on wellbeing is the numerous emotional repercussions of being ignored (Section 4.2 of this chapter), stressed by individuals and organisations alike (ARM, 2010; ASAN, 2014; NAS, 2011a; Wallis, 2012). Consequently there is a need for these to be acknowledged and addressed appropriately, since the presentation of autism is not generally grounded in the real lived experiences of autistic

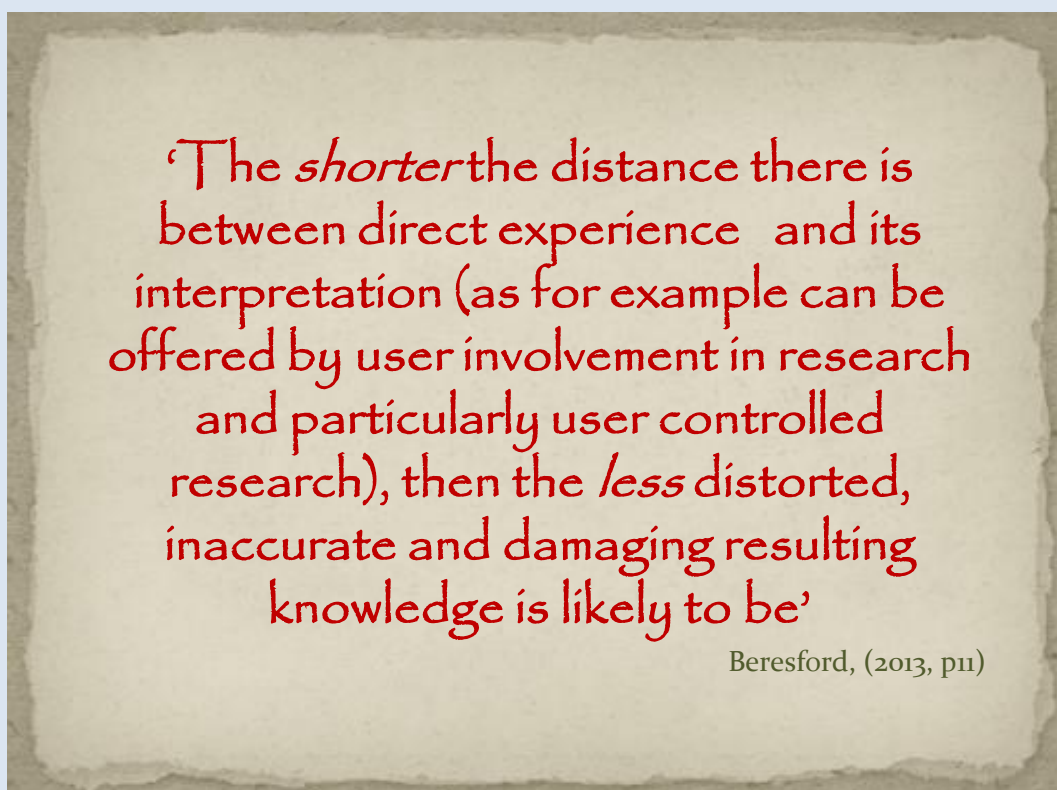
people (Waltz, 2005a). However, emerging individual and collective action is redressing this balance in the form of narratives of real lives (Baggs, 2003; Beardon and Worton, 2011; Chown, 2014b; Lawson, 2006a; 2008b; Milton, 2012a; Moxon, 2006; Murray, 2006b; Simone, 2010b). These now sit against the legislative backdrop (UNCRPD, 2006) and demand inclusive action: 'Nothing about us without us' (ASAN, 2014).



Figure 3: What is not heard (author's summary)

Inclusion of the autistic voice appears to have become divorced from any recognition that autistic people do have real lives. Autistic people have a right to be considered as 'more than autistic', have skills recognised (NAS, 2011b; UNCRPD, 2006) (NAS, 2011b) and have a right to equal access to services regardless of their identities (HMSO, 2010). Representation of the successes and skills of autistic/neurodivergent people is skewed as

many are students, parents, employees, employers, researchers and conference speakers (Arnold, 2012; 2014a; b; Brook, 2014; Dunn, 2014a; Graby, 2012; Hesmondhalgh and Breakey, 2001; Jackson, 2006; Lawson, 2003; 2006b; Milton, 2014b; Milton and Ridout, 2014; Moon, 2014a; Murray, 2006b; Murray and Aspinall, 2006; Ridout et al., 2011; Simone, 2014). Critically, the agenda being driven by autistic activists does reflect a diversity of views, encourages debate (ANI, 2000; ASAN, 2014; Autscope, 2014; NAS and Ask Autism, 2014; Ne'eman, 2011; Ridout, 2013b) and is covered by legislation (UN, 1948; UNCRPD, 2006). Yet this is rarely mentioned among the prevailing discourse of dependency, a view also taken by Beresford (2013b):



Shifting the balance thus from user involvement in research to user controlled research, might serve to address the discrepancy between what

autistic people say and what is heard (Milton and Bracher, 2013), impacting more positively on their wellbeing. It can be argued that challenging the location of power, therefore, through democratic processes needs to be at the heart of service provision, and central to this should be the inclusion of the autistic voice.

This links to diagnosis and the provision of information and support as required by the Autism Strategy (DoH, 2010a) and guidelines (NICE, 2010). Both recognise that some choose not to follow the route of formal diagnosis, but self-diagnose as autistic and have an equal right to access required services accordingly. Many autistic individuals who have managed to deal with issues of sensory overload and different communication preferences, for example Williams (1999b), Grandin (1995), Lawson (2003) and Isaacs (2014b) have further challenged the need for solely medical services. For this reason, a wider service agenda focus is surfacing, increasingly informed by autistic people, and placing a demand on services to adapt.

The emotional cost of imposed categorical distinctions on a multi-dimensional reality (Berney, 2006) and the resultant exclusion from opportunities can be devastating. This has been experienced personally by me and also discussed with family, friends and colleagues (Autscope, 2014; Milton, 2013; Ridout, 2013b) and evidenced in my professional work (A.C.T., 1998; Ridout et al., 2011). The very real impact of the exclusion of disabled people has led researchers from the field of Critical

Disability Studies, such as Reeve (2004) and Goodley and Lawthom (2005), to argue that, as with other identities of age, race and sexual orientation, disability can be considered as a form of social oppression. Furthermore, society's imposition of an agenda of normalcy on autistic (and disabled) people has furthered silenced the autistic voice (Milton and Moon, 2012; Reeve, 2002) resulting in services being inappropriate (ARGH, 2014; ARGH and HUG, 2011; Beardon et al., 2009).

Whilst the introduction of the Autism Strategy emphasised the need to train frontline staff in autism awareness (DoH, 2010a), the question regarding responsibility for training delivery remains contentious (Milton, 2011b; Milton and Bracher, 2013). Many autistic activists and individuals are clear that this should be presented and explained by autistic people themselves, since they are the experts in matters pertaining to their experiences of autism and their support requirements (Beardon et al., 2009; Milton and Moon, 2012; Milton, 2014d).

The real situation today is that the narrative of autism has been hijacked (ARGH and HUG, 2011; Arnold, 2012; McGuire, 2011), by the voice of non-autistic others (Baron-Cohen, 2000; 2008; Eysenck and Rachman, 1965/2007; Happe, 1994b; Wing and Gould, 1979). In other words, it is the non-autistic voice that is seen as the expert. This has had a profound impact on the framing of autism, as demonstrated by the language and terminology employed. Furthermore, it originates in the traditional methods of including/excluding marginalised groups and still pervades

organisations such as the National Autistic Society, who despite establishing the first UK autistic led conference (NAS and Ask Autism, 2014), maintain their policy of using the term 'person with autism'. This ignores the fact that many autistics consider people first terminology offensive on the grounds that autism is a core part of their identity (Sinclair, 1992; 2007).

Historically, involvement of marginalised groups has been scarce in public debate due to power inequalities such as those mentioned by Fraser (1987) in relation to gender. However, different approaches to involvement have materialised. One such, the Ladder of Participation (Arnstein, 1969) comprises 8 steps, which serve to depict the categorical levels of citizen power:



Figure 4: Arnstein's Ladder of Participation

Applying this to autism, through the redistribution of power, autistic citizens presently excluded from political and economic processes would progress from a situation where the 'manipulated have nots' are considered to be the expert voice (Milton and Moon, 2012; Reeve, 2002; Reeve, 2004) and 'deliberately included in the future' (Arnstein 1969, p216). Projects such as the autistic-led residential conference, *Autscape* (Autscape, 2013), the autistic-established journal, *Autonomy: the Journal of Inter-disciplinary Autism Studies* launched by Arnold in 2012, and the Theorising Autism Project (TAP, 2012; 2014) are essentially about taking this final step. These projects reflect autistic/neurodivergent ownership

and management as regards key decision-making, but funding remains an issue.

I would argue that although this approach does represent a necessary shift in power, there remains an essential lack of debate between autistic and non-autistic people and key contributions each might offer at all levels of service provision. So whilst progression up the Ladder of Participation may reflect an increasing willingness by some to listen to autistic voices, it does not necessarily tackle cultural differences, discriminatory and provocative terminology or even an understanding of the social barriers to inclusion. However, another approach, which may fill this gap, is the concept of co-production (Needham and Carr, 2009):



Figure 5: Co-production

As a response to pressures for reform, co-production concerns the delivering of public services 'in an equal and reciprocal relationship between professionals, people using services, their families, and their neighbours' (Stephens and Michaelson, 2013, p159). As such, it places an emphasis on the empowerment of both service users and providers, acknowledges the diversity of service users and is 'a potentially transformative way of thinking about power, resources, partnerships, risks and outcomes' (Needham and Carr, 2009, p1). This approach does not involve tokenistic consultation, as seen in Arnstein's Ladder of Participation (Arnstein, 1969), and service provision is seen in terms of successful frontline person-centered relations as opposed to mechanistic delivery, which may or may not be relevant and accessed.

Although, Needham and Carr (2009) identify, three types, critically co-production is characterised at its most effective by an active participation by service users, including autistic people at all decision-making levels, and this fits well with the argument being voiced by many autistic people (Brook, 2014; Grandin, 2000; Milton and Bracher, 2013). As an approach which is *not* tokenistic (Beresford, 2013b), but one that recognises the skills and contributions of individuals, co-production has much to offer in terms of providing autistic people with real opportunities to contribute to the reshaping and improvement of services (Stephens and Michaelson, 2013).

Perhaps one of the biggest benefits of co-production is that it recognises that if innovation is to be of real value, it involves taking risks (Stephens and Michaelson, 2013). As such, the devolvment of power to autistic people at levels of governing and management of projects should be effected. This might be evidenced through expenses being paid to autistic people to speak at or lead conferences such as TAP (2014). However, it is predicted that this change will unsettle many power-holders as power relations are challenged (Carr, 2007). It is also suggested that real change will only occur with participation of [autistic] people at every stage (ARGH and HUG, 2011; Needham and Carr, 2009).

The benefits of an approach based on co-production as opposed to the Ladder of Participation can be summarised as follows:

Co-production vs the Ladder of Participation	
Co-production	Ladder of Participation
<ul style="list-style-type: none">As a response to pressures for reform, co-production concerns the delivering of public services 'in an equal and reciprocal relationship between professionals, people using services, their families, and their neighbours' <p>Stephens (2013, p159)</p>	<ul style="list-style-type: none">An equal and reciprocal relationship between professionals, people using services and their families is never truly reached as there is always a level of power embedded

Figure 6: Co-production vs the Ladder of Participation (author's summary)

The power shift is an advantage that would certainly acknowledge the views of many autistic people, although for some, it may not go far enough (ARGH, 2014; ARGH and HUG, 2011; Milton and Bracher, 2013). Whilst the Ladder of Participation may illustrate a range of steps characterised by a power shift, power is always present in this approach. Nevertheless, I would argue that a co-production approach to service provision poses numerous challenges for all parties and takes time, willingness, honesty and a certain degree of creativity.

Shaping of services to date, as mentioned previously, is generally informed by non-autistic others, for example parents, practitioners, researchers and service providers.



Figure 7: Voices currently shaping services

Parents

Currently, the parental voice generally takes precedence over that of children and young people, and is characterised by reported dissatisfaction concerning information given at the time of diagnosis (Howlin and Moore, 1997). Additional concerns relate to quality and accuracy of information following diagnosis with changes over time (Osborne and Reed, 2008). Whilst an absence of information can provoke parental emotional distress due to a lack of support for the autistic individual and the family as a whole (Hare et al., 2004), the tendency to situate autism within a medical model of disability (Ambitious About Autism, 2014; Baron-Cohen, 2008) further contributes to parental distress (Ryan and Runswick Cole, 2008).

Many parents work hard to challenge social barriers and negative attitudes, preferring to 'recognise their child's abilities and strengths' (Dobson et al., 2001). However, there are social processes which impact negatively on discourse around disability as is evidenced in the positioning of practitioners as the expert. This can lead to the uncritical adoption by some parents of the framing of autism as a dysfunction, with the accompanying use of negative language as perpetrated by practitioners (Sinclair, 1993). Since the accurate shaping of services depends on consideration of terminology preferences of autistic people and their families, this should, therefore, be more apparent (Lester and Paulus, 2012).

Researchers

Pellicano et al. (2013) reported that despite opportunity for research to have a very real and positive impact on the lives of autistic individuals, autistic people, their families/carers may hold a different perspective. Furthermore, reluctance by many autistic individuals and their families to engage with research as participants was linked to a failure to disseminate study findings or focus on their priorities, namely 'research on public services, life skills, cognition and learning and the place of autistic individuals in society' (Pellicano et al., 2013, p4). Questions arise, however, around methods utilised to engage with autistic people and value their experiences in order to act on these (Arnold, 2014b; Brook, 2014; Milton and Bracher, 2013; Ridout, 2013c; Ridout, 2014a).

Research findings from organisations and funding bodies such as the ESRC (2014), Autism Speaks (2014), Autistica (2014) and Research Autism (2014b) inform policy and practice. For this reason, it is critical that studies include and reflect the views of autistic people at all levels of the research process (Milton, 2011b; Moon, 2014c) as it has a direct impact on people's lives (Richardson, 1995). There are increasing numbers of autistic people who have completed research or are currently engaged in it, and who, as a result, have managed to reshape certain aspects of the research agenda, such as terminology, and provide an insider perspective (Holliday-Willey, 2006; Lawson, 2010; Milton, 2012a; Murray et al., 2005). Difficulties arise, though, if autistic people are not

involved at all levels of the research process, as studies are more likely to have a deficit focus and impact negatively on wellbeing (Naidoo and Wills, 1998; Seedhouse, 1997). This links back to the issues discussed in relation to my research questions on identity and wellbeing (question 2) and context and power (question 3), and reflects a theme explored using my data, namely whether use of different sites of analysis impact on meaning-making.

Practitioners

Uncritical acceptance of practitioners as the experts as opposed to autistic-led involvement focused on wider social solutions lends itself to the development of unsatisfactory, irrelevant and costly provision (DoH, 2010a; NAS, 2011b). Much of the practice engaged in by health care services is based on 'guesswork, personal preference, tradition, professional modelling and fear of litigation' as opposed to considering its 'appropriateness, effectiveness and safety' (Oakley, 1999, p249). Furthermore, Oakley asserts the association between social contexts and trends and epistemological and methodological positions. An example of this in the field of autism is evidenced by a lower attention paid to the support requirements of women and girls (Gould and Ashton-Smith, 2011).

My view of Participation

In essence, processes to develop services should come to the very heart of issues pertaining to democracy, and challenge where power is actually

situated. This is a key part of my study, and as a researcher in the area of autism, I see participation as a two-step process. The first step should acknowledge that autistic people are still a marginalised group, and that certainly among autistic activists and authors discourse emphasizes neurodiversity (Arnold, 1999; Graby, 2015; Robertson, 2010a). Inclusion of the autistic voice at all levels of debate may initially prove difficult as disenfranchisement often brings with it a lack of trust. However, the placing of autistic people as the experts in their experiences (Beresford, 2013b; Milton and Bracher, 2013) so that voices can be heard and listened to is, I would argue, fundamental to success. This first step can be illustrated as below, with autistic people placed as the experts and key stakeholders around the outside. This step, I consider to be crucial, as to build trust among disenfranchised [autistic] people, time needs to be given to listen to what they have to say:



Figure 8: Researcher's view of participation – step 1

The second step of this participatory process draws together the views of autistic people and non-autistic stakeholders in a collaborative process, and it is vital for the voice of autistic people to remain the expert voice on autism. However, the development is that there is acknowledgement of the skills, abilities and real lives of individuals. The characteristics of this step of the process are critical if consideration of the NICE (2013) guidelines is taken into account regarding older people and mental wellbeing. This is a policy concerning quality statements regarding care, and which can be translated into service provision which fits in with my research. The statements are illustrated below:

What should autistic involvement be like?

- Participation in meaningful activity
- Personal identity
- Recognition of mental health/physical conditions
- Recognition of sensory challenges/impairments
- Access to healthcare services
- Diversity, equality and language

Figure 9: What should autistic involvement be like? (author's summary)

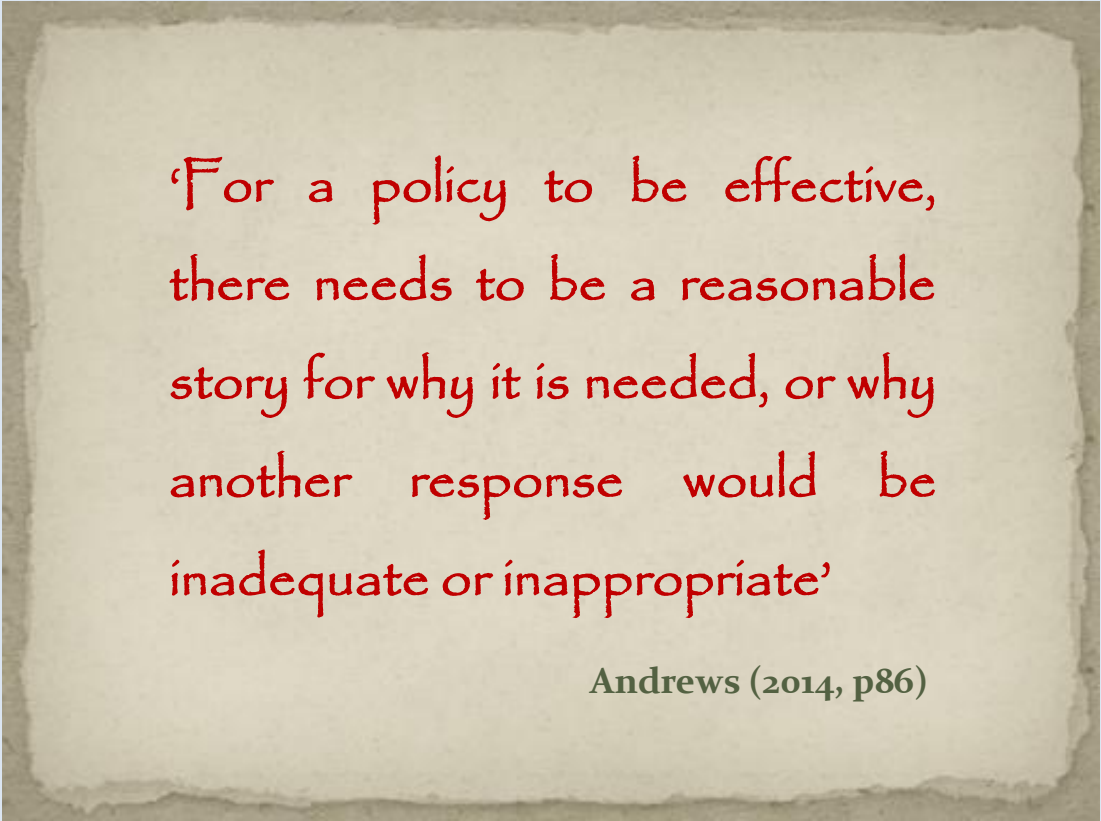
Consequently, the second step of the participation process that I envisage demonstrates an opportunity to build on aspects and roles that autistic people already fulfill and paves the way for progress in all areas. This can be represented as in the following diagram:



Figure 10: Researcher's view of participation – step 2

I now locate the autistic voice in the context of legislation and discuss its relevance and implications.

Section 2: Policy and Legislation setting my Study Context



‘For a policy to be effective,
there needs to be a reasonable
story for why it is needed, or why
another response would be
inadequate or inappropriate’

Andrews (2014, p86)

The reasonable story in relation to this study is that many autistic individuals have a poor quality of life (Plimley, 2007; Ridout et al., 2011), are disenfranchised and excluded from social opportunities (aspie rhetor, 2015; Milton and Bracher, 2013; Shepherd, 2008) and that legislation is not being implemented.

Development of autism-specific legislation began in 2008 with the National Autistic Society (NAS) ‘I Exist’ campaign informed by autistic adults, parents/carers, local authorities and Primary Care Trusts (PCTs). Aimed at improving support for autistic adults due to serious concerns around their mental wellbeing and access to employment, the findings, a

Bill brought by Cheryl Gillan MP in 2008, and two NAO reports then fed into the Autism Act (HMSO, 2009).

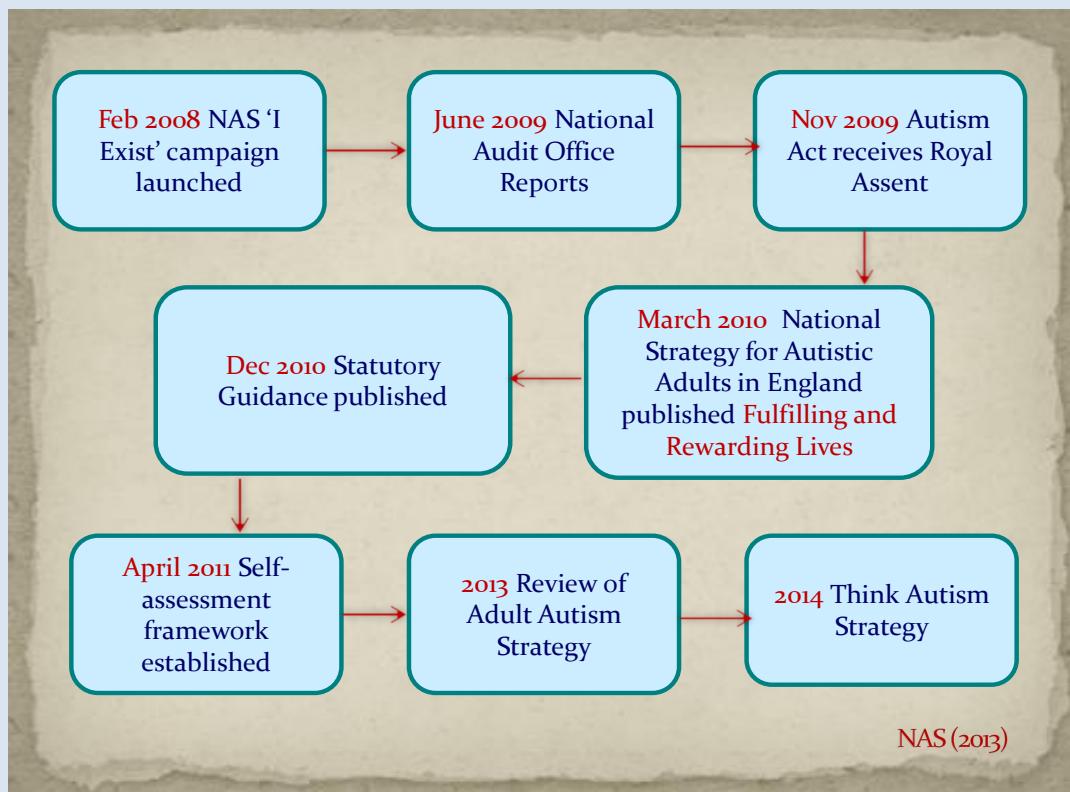


Figure 11: Developments in autism specific legislation

Despite the view held by many autistics (Grandin, 1995; 2009; Milton and Moon, 2012; Murray et al., 2005; Sainsbury, 2009), the NAO reports located autism within a medical model of disability and embedded assumptions, ignoring family support and skills among autistics (Knapp et al., 2009). However, the Public Accounts Committee report (PAC, 2009) emphasised employment, transitioning, a lack of strategic planning among local authorities and health bodies regarding staff training and the requirement for a clear diagnostic pathway.

The Autism Act (HMSO, 2009) aimed at reviewing public services support for autistic adults, placing the two key duties on the government:

1. Production of an adult autism strategy for England by the end of March 2010.
2. Production of statutory guidance (legally binding) for local authorities and health bodies by the end of December 2010.

The ensuing Adult Autism Strategy (DoH, 2010a) and Statutory Guidance (NICE, 2010) highlighted key areas to address: training frontline staff in autism awareness and understanding; developing a clear diagnostic pathway with an offer of individual assessment of support requirements; independent living support; improved work opportunities; transitions between child and adult services; and local planning and leadership concerning the development of appropriate services.

Criticisms of this legislation by some autistic people related to 'failure to demand real change from public bodies', lack of pressure on local authorities to establish uniform partnership boards and diagnostic services at a national level, and a lack of regional monitoring to facilitate a comparison of national standards (ARM, 2010). Transitional support from child to adult services has been described as chaotic, with legislation imposing pre-existing categories of learning disability on autistic individuals (Dunn, 2014a). As councils buckled under increasing economic constraints, some autistics received no support (SCIE, 2013; 2014).

Further criticism concerned a lack of understanding of 'neurodiversity', or the existence in us all of an uneven, or 'spiky' profile in terms of processing information, (ARM, 2010). This is key to acknowledging different ways of functioning among individuals and encouraging the building of improved environments, especially in relation to sensory and social overload. However, the Equality Act (HMSO, 2010) indicates implementation of disability access legislation to be simply one of many hurdles to overcome in terms of access and reasonable adjustment. Although the NAS were less critical of the Autism Strategy, there remains a real concern among autistic individuals and practitioners for the autistic voice to be heard at all levels, with a role in leading and delivering staff training (ARM, 2010; Arnold, 2014b; Brook, 2014; Dunn, 2014a; b; Milton, 2011b; 2014a), particularly as 'expertise' is considered to be in the hands of non-autistic practitioners (Dunn, 2014a).

A failure to guarantee support or services following a diagnosis of autism is also of concern (Beardon and Worton, 2011; Edmonds and Beardon, 2008; Murray and Lesser, 2006; NICE, 2010; Ridout et al., 2011). With the removal of Asperger syndrome from the DSM-V (Giles, 2013; Kaufmann, 2013), a classification of mental disorders used by practitioners, many individuals feel a loss in identity and worry about reduced access to support, resulting in dependency.

The Autism Act (HMSO, 2009) aimed at opening opportunities to address gaps in service provision for autistic individuals, but has faced challenges in respect of law, policy and resultant practice in a range of areas (Greenfield et al., 2011; Scally and Donaldson, 1998; Tidball, 2011), including health and adult social care (Lasker et al., 2001). Furthermore, leadership issues, the introduction of new legislation (such as the Personal Independent Payment), absence of case law, changes in the Legal Aid system, increasing barriers in local authority social work and limited resources for implementation have created increasing problems for practice (Tidball, 2011). However, despite varied regional developments in terms of service provision, the NAS (2013) reports progress. This is enhanced by new proposals introduced by Think Autism (DoH, 2014c), and autism awareness training prioritised by GP's for the next three years and for all mainstream healthcare professionals and Job Centre disability employment advisors.

In addition to this legislation, other key legislation impacts on my study:



Figure 12: Other key legislation

The United Nations Convention on the Rights of Persons with Disabilities (CPD) (2008), a human rights treaty ratified by the EU in 2010, contributes by emphasising a need for autism awareness and protection of the rights of autistic individuals and accentuating training to address systemic failings and responsibilities. Furthermore, the UK government has committed itself to ensuring that these rights are fulfilled (EHRC, 2008). The Equality Act (2010) assembles nine pieces of legislation pertaining to protected characteristics (age, disability, gender reassignment, race, religion or belief, sex and sexual orientation, marriage and civil partnership and pregnancy and maternity) asserting their equal value. This development accepts combined discrimination on the basis of two or more of these characteristics and embracing the

diversity of identities to which individuals subscribe. It places a responsibility on the public sector to provide appropriate services accordingly. This is critical for my study, since autism research and practice has tended to focus on a single identity, namely that of being male (Gould and Ashton-Smith, 2011) and by ignoring additional identities there is an inherent denial of the influence of these on individuals in terms of their real lives. This welcome turn in legislation is now mandatory within training content.

The Care Act (2014), whilst not providing a framework for my study, responds to the need to safeguard adults in receipt of care provision and sets standards for this. Furthermore it connects with health education, research and health services, which impact on autistic adults by focusing on wellbeing. A key aspect of this Act is provision in relation to transition between services, for example from a care to a community setting, or child to adult services, and attention to assessments, direct payments and staff training is embedded.

Impact of Ignoring Legislation

- Impacts on the wellbeing of autistic people
- Denies autistic people the opportunity to use and develop their skills and knowledge and contribute to society
- Forces many autistic individuals into a life of dependency on benefits/family members

Figure 13: Impact of ignoring legislation (author's summary)

Despite the existence of this legislation, autistic individuals experience damaging effects due to a failure in implementation as reflected in the numbers accessing mental health services (Andrews, 2006; Beardon and Worton, 2011) and across many employment settings, which deny autistic individuals the opportunity to utilise their skills (Mills et al., 2010; NAS, 2011a). Employers' failure to make reasonable adjustments renders many autistic people anxious, and with experiences of heightened sensory and social overload may lead to an inability to work (Hesmondhalgh, 2006; Meyerding, 2006; Simone, 2010a). Consequently, many autistic people resort to a life of dependency on family and benefits.

In summary, there is now autism-specific legislation in place, which, although criticised by autistic activists (ARM, 2010), is also supported by others (NAS, 2013). Critically, the impact of *not* implementing legislation denies autistic people their rights to live fulfilling and rewarding lives, and this is a theme which feeds into the theories of autism and models of disability discussed in the following section.

Section 3: Literature Review and Theory

3.1 Autism theories

Theories introduced since Bleuler coined 'autism' in 1911 (In: Arnold, 2012; Moskowitz and Heim, 2011) have had considerable power over the lives of autistic people, including developments in scientific areas such as neurology, biology and genetics. However, the rationale underpinning many is one of 'normalising' the Aspie to reduce society's discomfort, as opposed to addressing the discomfort of the Aspie (Andrews, 2006).

My study focuses on plurality of voice and the insider experience, and I locate autistic theories as a plausible response to imposed outsider theories. I then highlight key points characterising the medical and social models of disability and their impact on autistic people. Finally, I introduce the debate on neurodiversity.

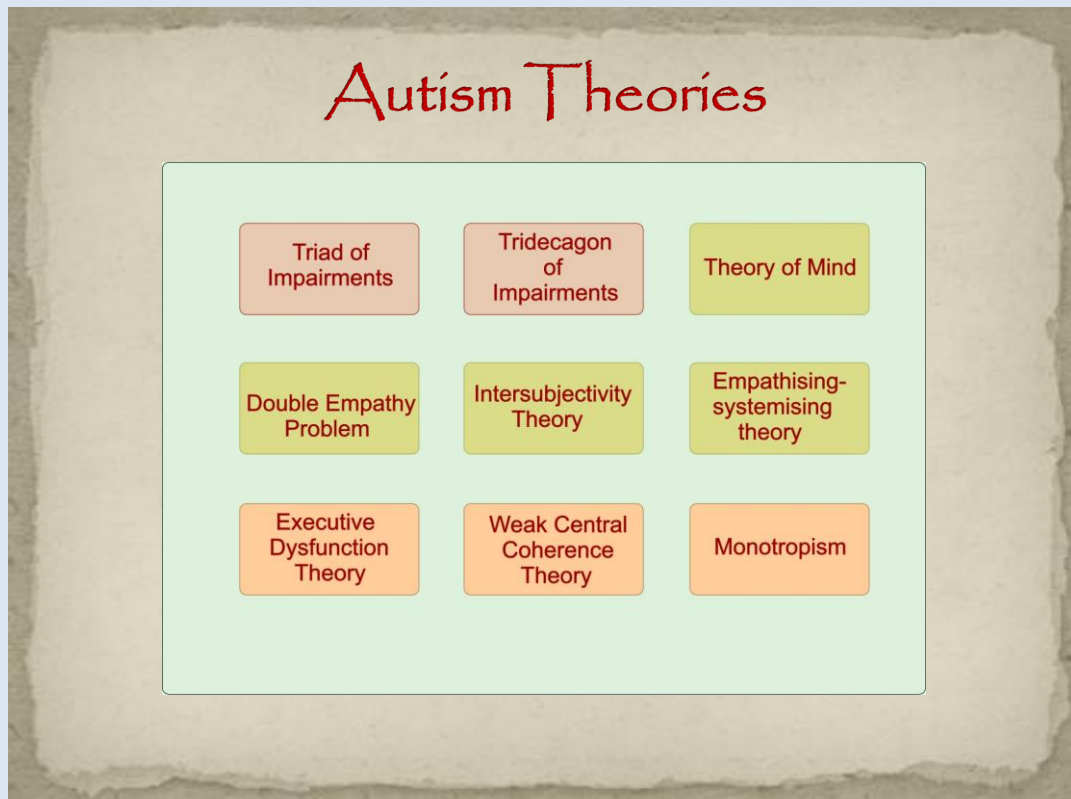


Figure 14: Autism theories

I have placed the theories depicted in three groups as follows:

Group 1 focuses on specific challenges.

Framing autism as a '**triad of impairments**' in terms of social interaction, social communication and imagination/repetitive interests and activities (Wing and Gould, 1979), is a theory with immense power over the lives of autistic people, and one which characterises the contemporary definition. A response from an insider perspective, suggests that no model can sufficiently describe the experiences of humans, autistic or non-autistic (Hesmondhalgh, 2006, p39). Nevertheless, Hesmondhalgh proposes his model, **a tridecagon of impairments**, to reflect his own

changing lived experiences, stating that ‘throwing away inflexible models and theories remains a scary thing to do in any walk of life.’ This is illustrated below:

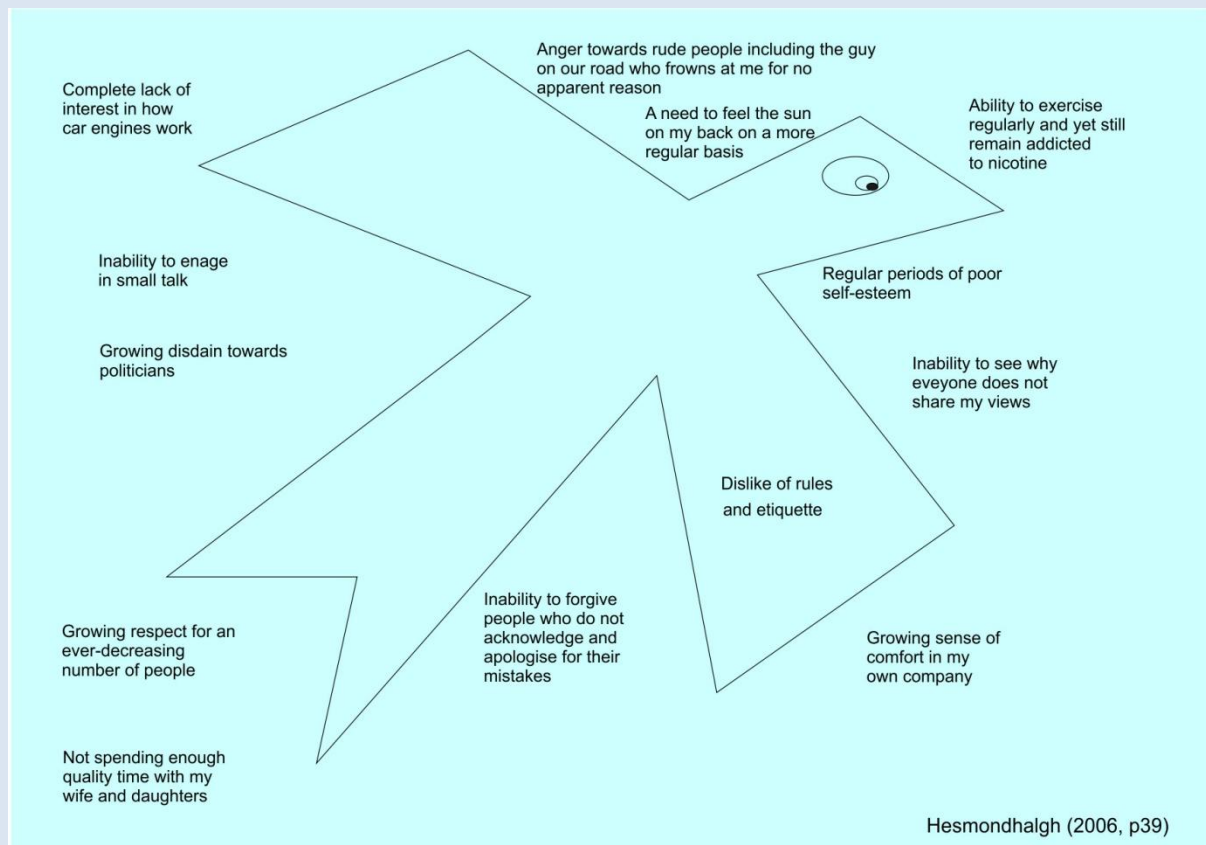


Figure 15: Hesmondhalgh's Tridecagon of Impairments

Group 2 centres on empathy.

Notions of an impaired **Theory of Mind (ToM)** (Baron-Cohen et al., 1985b), **Empathising-Systemising Theory** (Baron-Cohen, 2008) and **Intersubjectivity Theory** (Trevvarthen and Aitken, 2001) all point to a deficit in autistic people in relation to empathy and intentionality. However, an insider perspective proposed by Milton (2012a) claimed that rather than situating autism in a one-way cognitive-behavioural discourse, it was more accurate to acknowledge lack of empathy as a

two-way process, or **a double-empathy problem**, raising questions about challenges faced by autistic and non-autistic people regarding reciprocity and mutuality.

Group 3 considers focus of attention, interest and processing of information.

Weak Central Coherence focuses on interest in detail (Frith and Happe, 1994; Shah and Frith, 1993) and **Executive Dysfunction**, which proposed a difficulty in attention sifting (Baron-Cohen, 2008, p52), situating this difference experienced by many autistic people within a deficit framework.

The insider theory responding to these is **Monotropism** (Murray et al., 2005), which emphasizes a different cognitive processing style with tightly focused attention available for tasks. Accounts of experiences produced by other autistic authors also support this theory (Grandin, 1995; Williams, 1999b).

3.2 Medical model of disability

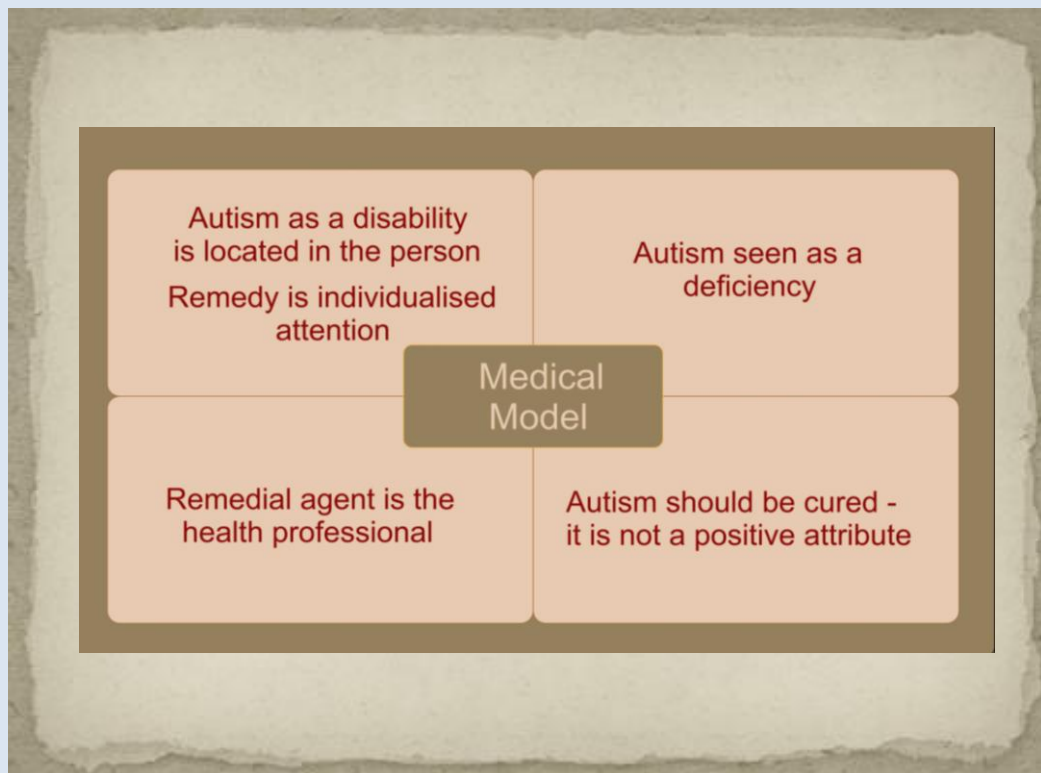


Figure 16: Medical model of disability

The medical model of disability was the first to influence perceptions of autism and continues to impact on the field with discussions around curative medical interventions characterised by a 'top down', 'expert professional-led' approach (Attwood, 1998; 2007; Baron-Cohen, 2008; Happe, 1999 ; Research Autism, 2014a; Shah and Frith, 1983). With an emphasis on the dysfunctional nature of autism, this model is contested by many autistic people and their families (Brook, 2014; Lawson, 2008a; Milton and Moon, 2012; Murray, 2006a). Furthermore, the damaging effect of negative language conjured up by this model comprises images of 'normality', increasingly challenged by autistic people (Sinclair, 2012).

Critically, the medical model fails to address the narratives of autistic and neurodivergent individuals as told by them and skews the contexts of their experiences (Arnold, 2010; 2012; Milton, 2010; Milton and Moon, 2012; Milton and Ridout, 2014; Sainsbury, 2009; Williams, 1999a; b; 2007). Consequently, the bias offered encourages a societal perception of autistic people as problematic, ignoring their challenges and failing to respond to their support requirements appropriately (DoH, 2010a; 2014b; Milton and Bracher, 2013).

My position is that use of the word 'cured', or even 'mitigated' reflects the prevailing wider non-autistic practitioner situation today, as their power frequently denies the lived experiences of autistic and neurodivergent people (Dawson, 2004; Research Autism, 2014a). The assumption by many that the majority of the medical profession are engaging with autistics is not borne out in reality (TAP, 2014), and inclusion of the autistic voice remains tokenistic (Arnold, 2014b; Beardon et al., 2009; Beardon and Worton, 2011; Mills et al., 2010; Milton and Bracher, 2013).

3.3 Social model of disability

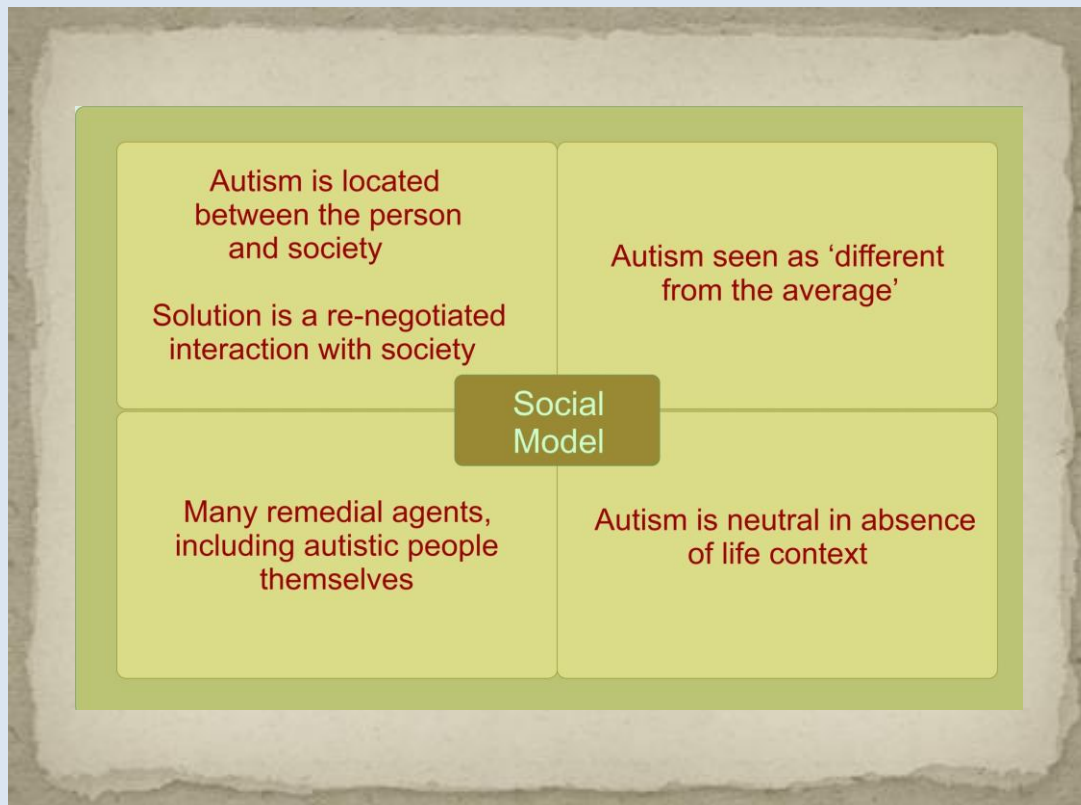
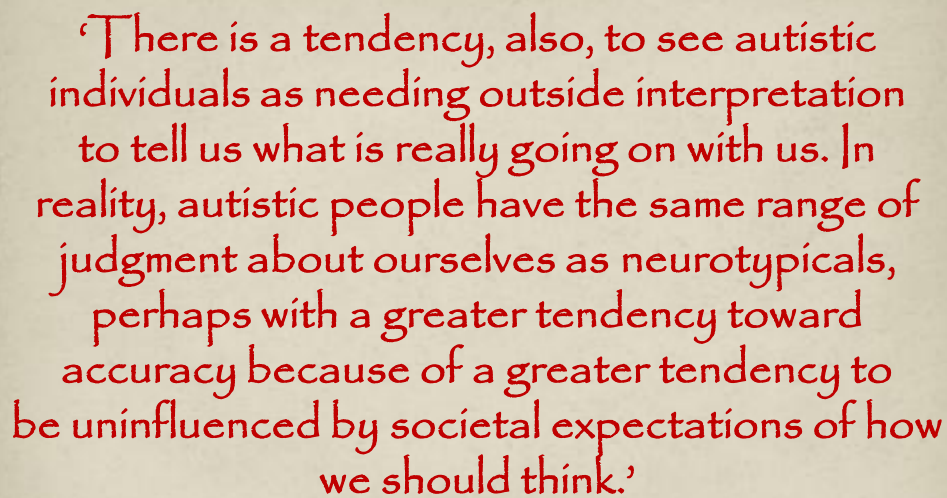


Figure 17: Social model of disability

Current debate propelled by autistic voices emphasizes that autism can no longer be explained satisfactorily by the medical model of disability, since autism relates to differences and not deficits. For example, different ways of processing information (Lawson, 2011; Murray et al., 2005); a double empathy problem (Milton, 2012a); and a tendency towards the outsider approach in research (Milton, 2010). As Baggs (2003) states:



‘There is a tendency, also, to see autistic individuals as needing outside interpretation to tell us what is really going on with us. In reality, autistic people have the same range of judgment about ourselves as neurotypicals, perhaps with a greater tendency toward accuracy because of a greater tendency to be uninfluenced by societal expectations of how we should think.’

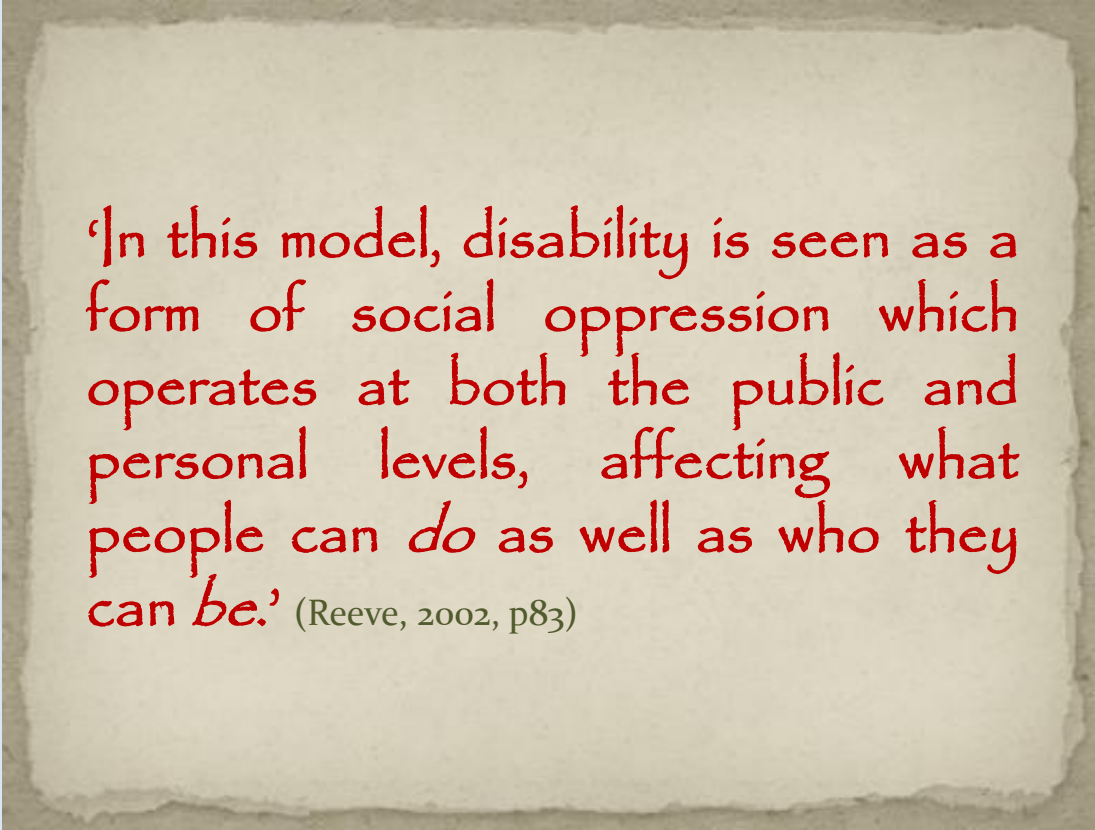
Baggs (2003) <http://archive.autistics.org/library/autopin.html>

More widely in the field of disability, the emergence of the social model in the 1970s established itself in direct opposition to the restrictions and oppression imposed by the medical model (Finkelstein, 1975; Oliver, 1990; Oliver, 2013; UPIAS, 1976), and challenged views held by the majority of professionals and service providers (Shakespeare, 1993a; b). The separation of impairments (individual medical requirements) from services required by all (housing, education and employment) has had considerable influence on more contemporary perceptions of autism and current research in the field (Mills et al., 2010; O'Neil, 2008). Recognition of influential negative attitudes and systemic barriers, and the introduction of context by this model have sharpened debate on experiences of a neurodiverse society, and 'label-locked thinking' is more readily confronted (Baker, 2014). Diverse terminology used by autistic

individuals themselves, reflecting autism as integral to their identity, is a major acknowledgement of this model (Sinclair, 2007) as is an emphasis on the numerous attributes of autistic individuals (Bogdashina, 2003, p28).

This model's failure to account for the varied experiences and cultures of disabled people, due to an emphasis on socio-structural barriers, has been raised (Shakespeare, 1994). However, regarding autism, the last two decades have borne witness to the establishment of self-advocacy groups and autistic-led conferences, such as Autscope (in the UK) and Autreat (in the USA). Furthermore, social networking sites and blogs have facilitated circulation of an increasing array of perspectives from autistic individuals in matters that impact directly on them.

A further dimension of the social model introduced by Reeve (2002), relates to the psycho-emotional disablement of people. She states:

A quote is presented on a rectangular piece of aged, yellowish-brown paper with a deckled, torn edge. The paper is set against a solid light blue background. The text is written in a red, serif font. The quote is: 'In this model, disability is seen as a form of social oppression which operates at both the public and personal levels, affecting what people can *do* as well as who they can *be*.' (Reeve, 2002, p83)

'In this model, disability is seen as a form of social oppression which operates at both the public and personal levels, affecting what people can *do* as well as who they can *be*.' (Reeve, 2002, p83)

This perspective is illustrated and extended in relation to autism (Milton and Moon, 2012), and has implications for the development of fresh theoretical insights.

3.4 Neurodiversity

The neurodiversity paradigm focuses away from the medical model and towards theories such as monotropism, suggested by neurodivergent writers (Murray et al., 2005). Furthermore, as a concept, neurodiversity acknowledges naturally occurring human diversity and the socially constructed notion of a 'normal brain', or 'a brain that functions in a way that is 'cognitively correct' (Walker, 2014). At its core is recognition of variance at the level of the interrelationship between brain and personality. Whilst parallels exist between the inequalities and social

power manifested in other areas of diversity, such as sexual orientation, ethnicity and culture, creative opportunities are also available if neurodiversity is embraced (Walker, 2014).

The concept of 'normalcy' has provoked the debate on neurodivergence, or neurocognitive functioning at variance to socially determined 'norms', (Walker, 2014), and so neurodivergence begins a journey unashamedly without being pathologised. An extension of this is an 'autie-ethnographic' narrative (Yergeau, 2013) emphasizing the violence of ToM and the subsequent disembodiment of autistic people by ToM enthusiasts such as Baron-Cohen et al. (1985b). This is then situated within a feminist framework to challenge oppression more widely.

Baker (2006) describes features of neurological difference as being 'associated with individual or community identity that is a more or less elective choice of those experiencing neurological difference.' Another perspective draws attention to the 'us' and 'them' characteristics of neurodiversity, previously experienced by political groupings relating to class, gender, race and sexual orientation (Runswick-Cole, 2014). Fundamental to the advancement of thinking in relation to autism and disability is the right of individuals to own and express their diversity themselves. As Sibley (2014) observes:

"When one family member has autism, the whole family has autism". MY ASS. My autism is not about my parents or my siblings or my non autistic friends and extended family. It is my neurology. It is not theirs. No matter how much they listen to me, how much they try to understand, it is *not* about them...As long as it's considered to be our parents' thing, though, the system will continue to be broken."

Sibley (Dec 2010) <http://www.timetolisten.blogspot.co.uk/>

Sibley's view draws together that of many neurodivergent individuals who feel they have been disenfranchised, including this researcher, and whilst there is need for autistic or non-autistic individuals to access medical care at times, the neurodiversity paradigm perhaps sits best alongside the social model of disability with its challenge to attitudes and systemic barriers.

By no means a final word on neurodiversity, but one which opens the mind and tests the waters of acceptance and inclusion, is one expressed by one of the key autistic advocates in the UK, Larry Arnold:

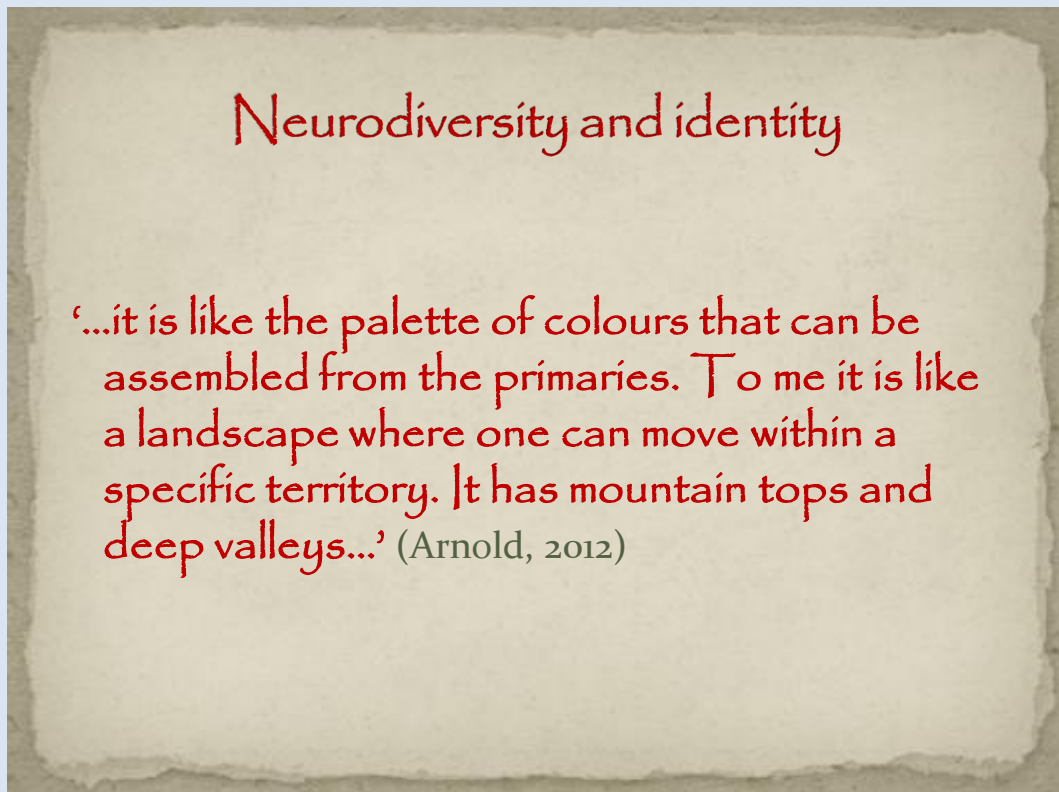


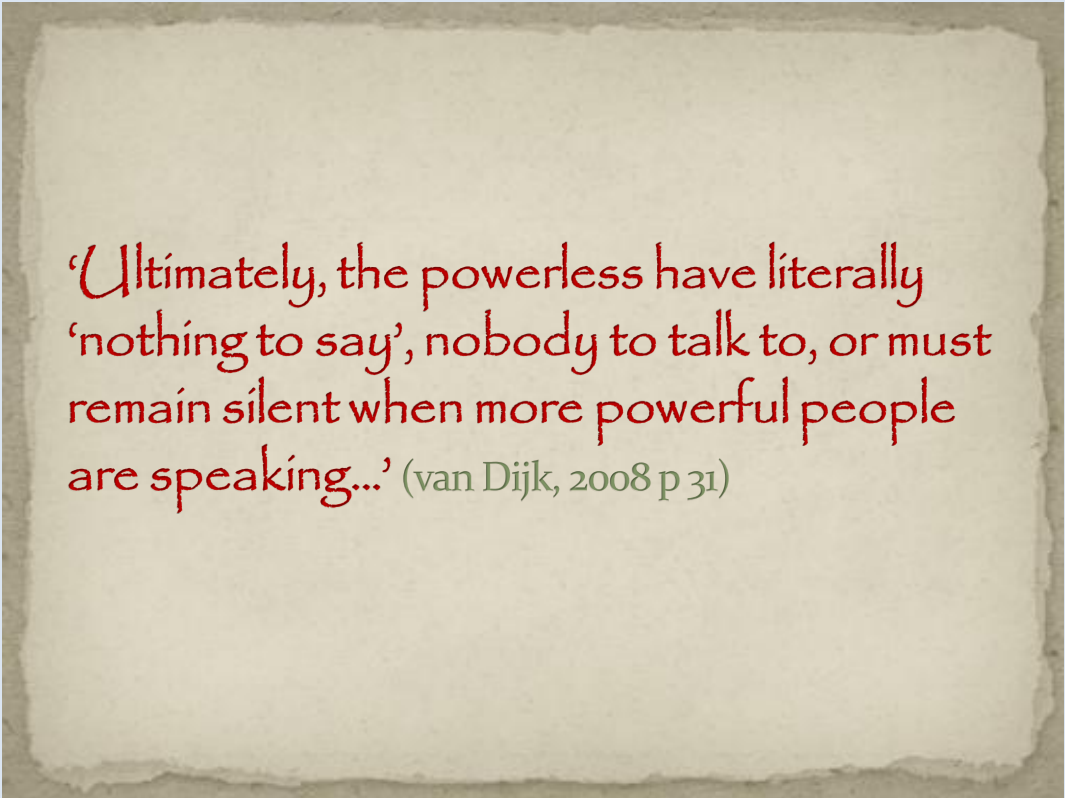
Figure 18: Neurodiversity and identity

The following section introduces key themes addressed by my research questions, namely identity, context, power and wellbeing. I discuss the location of the autistic voice within current debate and consider the need for a shift in focus.

Section 4: Key Themes Relating to my Research Questions

4.1 Identity, context and power

The first part of this section considers the formation and nature of identities and the influencing and shaping of these by context and power.



‘Ultimately, the powerless have literally
‘nothing to say’, nobody to talk to, or must
remain silent when more powerful people
are speaking...’ (van Dijk, 2008 p 31)

Those who are in positions of least power tend to have little access to written or verbal discourse and are subsequently unable to influence its reproduction (van Dijk, 2008). This can be seen in the shaping of services, typically not informed by autistic people, as power frequently remains in the hands of non-autistic service providers. Milton (2012a) argues that the framing of autism as a social deficit, as opposed to a difference in sociality, facilitates an agenda with ‘an idealised normative view of social reality’, thereby failing to adopt a holistic approach to understanding and including autistic people. However, increasing internet use has provided an opportunity for autistic people to come together, form communities, and at the very least have a dialogue amongst themselves as to the agenda they would like to advance on autism (ANI,

2000; ARGH, 2014; ASAN, 2014).



Figure 19: The autistic voice (author's summary)

The location of the autistic voice remains questionable in matters pertaining to autism; whilst the voice of some autistic people introduces new perspectives to debate on matters such as autism, disability and services (Arnold, 2012; Graby, 2012; Murray, 2014; Sinclair, 2007; Yergeau, 2010), that of others remains unheard (Milton and Bracher, 2013). This is a theme continually raised by autistic people (Baggs, 2003; Hesmondhalgh, 2006; Jackson, 2002; Sainsbury, 2009; Yergeau, 2013) and is corroborated by findings from Parsons et al. (2009), who also found that opinions are generally weighted in favour of the views held by adult powers.

Compartmentalising of autistic people according to perceived ability (Frith, 1989; Happe, 1991) has been shown to be unhelpful and limiting in terms of recognition of the skills and abilities of autistic people (Baggs, 2003; Grandin, 1995; Lawson, 2001; 2008b; Williams, 1999a; b; 2007; Yergeau, 2010). Moreover, imposed terminology may exacerbate an already distressing situation (Moran, 2015). This toys with the Foucauldian notion of power as regards the 'defining of others'. Foucault suggested that the confining of an individual, or the restricting of their behaviour, can be perceived as both a constraining limitation or productive in that restriction enables those in power to reshape the individual(s) concerned (Simons, 1995). Its usage as a tool, as in Applied Behavioural Analysis (ABA) introduced by Lovaas in the 1980's, by many non-autistic practitioners to persuade the autistic person that their behaviour should be 'normalised', has led autistic individuals, practitioners and researchers to question the ethics behind the constraining limitation of power in many interventions (Dawson, 2004; Jack, 2014; Milton, 2014e; Research Autism, 2014a).

The safety of identity is also questioned in relation to gender by Bornstein (2013), who demonstrated through posing a question on Twitter and a blog asking people to define themselves, that gender could *not* be neatly categorised as a binary. Rather, responses showed in excess of one hundred 'gender outlaws' (Bornstein, 2013, p147). However, an identity does not always bring solace, and Bornstein (2013)

explores the limitations of encasing ourselves in a specific [gender] identity shell, as this prevents growth, fluidity and new experiences.

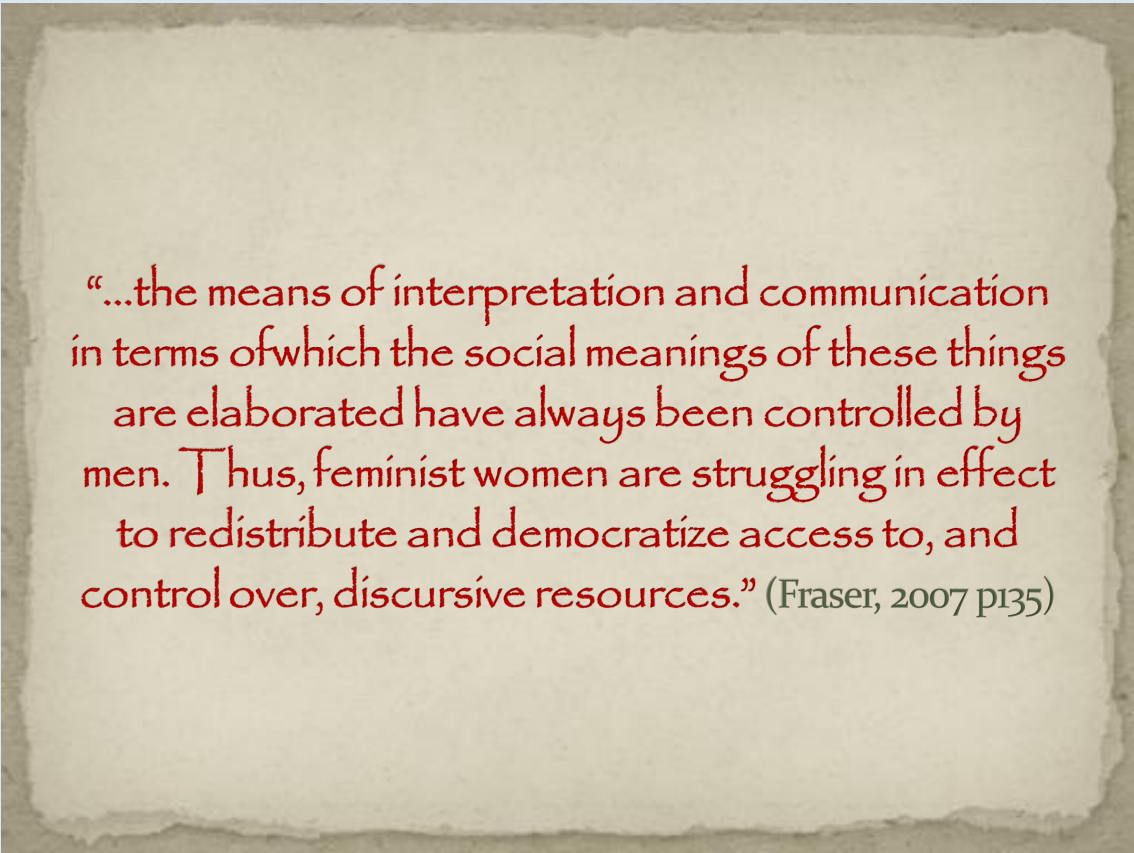
This can be translated to the limiting experience faced by many autistic people, who are regarded as solely autistic (King, 2014; Lawson, 2006a; Yergeau, 2010). Moon (2014c) questioned the safety of an identity, due to the frequent placing of people into categories pre-defined by non-autistic 'others'. In addition, Arnold (2014b) observed that autistics are at the beginning of a journey repeating struggles previously faced by other disabled communities. Struggles such as negative publicity and 'medical model' attitudes towards those perceived in some way as different must be challenged in order to introduce an agenda inclusive of autistic people. It would be reasonable, therefore, to question the safety of any identity, including that of autistic, due to its mercurial nature and the diverse interpretations of any single one identity. For this reason, it can be argued that power needs to be relocated so that individuals can describe and shape their own fluid identities.

Butler

‘...identity is not immediately *present* in a sign: it is by learning to use language situationally – which is itself a matter of linguistic differences and cultural conventions – that subjects project themselves into gender roles as women or men.’ (Elliott, 2009, p217)

Butler’s contribution to my research narrative also concerns the fluidity of identity, and she observes that it cannot be reduced to a sole concept as it is ‘a discursive event’ (Elliott, 2009). With discourse as a central theme to her arguments, Butler would probably recognise autism as fluid in nature, specific to individuals, dependent on context and continually emerging and developing discourse as to what constitutes autism or ‘an autistic person’. The autistic voice on fluid identities ties in with Butler’s position. Current arguments focus on autism as a difference as opposed to a disorder (O’Neil, 2008), and many employ the term ‘neurodiversity’ as it focuses away from the medical model. Both perspectives respond to specifics of sensory, social and intellectual differences relating to

individuals (autistic or non-autistic) and contexts (Arnold, 2012; Murray et al., 2005; Robertson, 2010a; Walker, 2014).



“...the means of interpretation and communication in terms of which the social meanings of these things are elaborated have always been controlled by men. Thus, feminist women are struggling in effect to redistribute and democratize access to, and control over, discursive resources.” (Fraser, 2007 p135)

Another feminist whose work informs my area is Fraser (2007) as she tackles Habermas’ failure to address inequalities in society, which subsequently points to issues relating to power inequalities. Fraser’s work acknowledges the make-up of the contemporary gender system, characterised by male dominance and female subordination, and which demonstrates how the female voice is scarce in public debate (Fraser, 1987). When applied to autism, Fraser’s influence on my study would question how the needs and aspirations of autistic people can be addressed if dialogic processes render their interests and voice invalid

(Elliott, 2009, p168). The prevalence of non-autistic voices over the autistic voice in matters pertaining to autism goes unrecognised in the context of this argument.

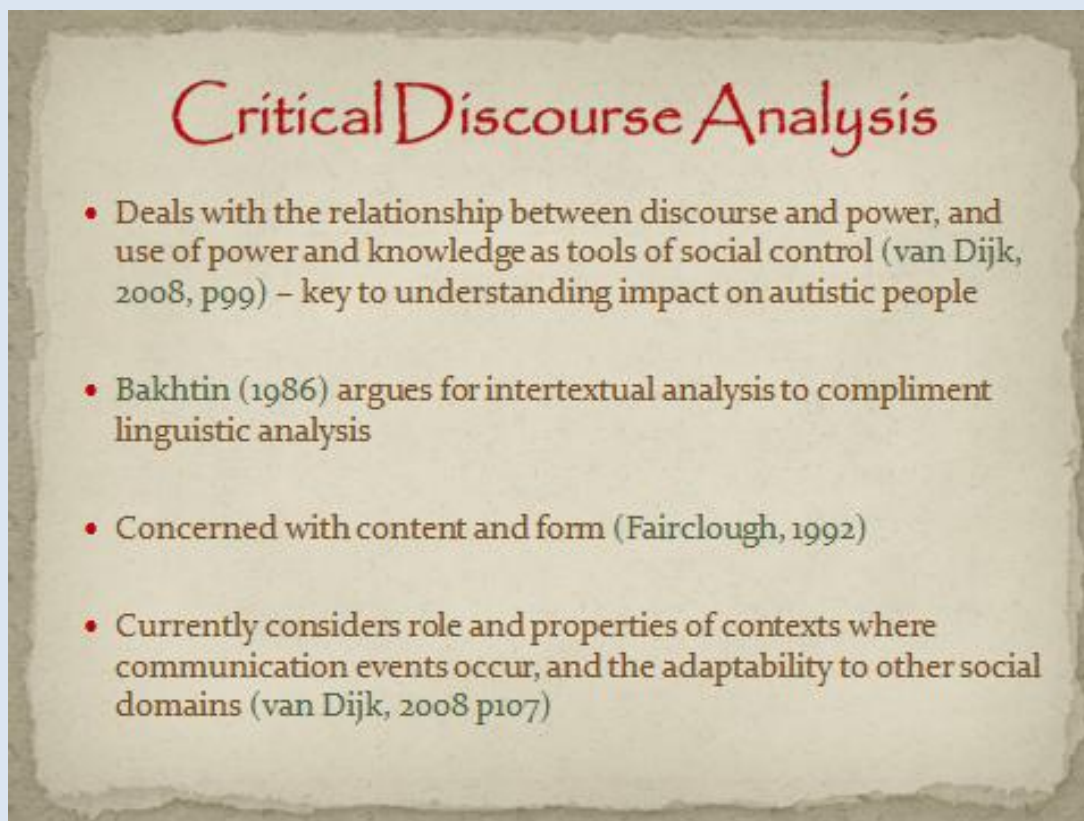


Figure 20: Discourse, power, context and semiotics (author's summary)

Critical Discourse Analysis (CDA) also contributes, as it views discourse as 'an integral aspect of power and control' (Bloor and Bloor, 2007, p4) and acknowledges contextual diversity regarding meaning-making, or language (Fairclough, 2009). This diversity would be expected to yield various social perspectives, and Fairclough argues that the term 'semiotics' more accurately encompasses the range of expressive modalities used: language, visual image and body language. This position advanced his earlier argument, that textual content cannot be properly analysed without simultaneously analysing its form (Fairclough, 1992), a

point expressed earlier by Bakhtin (1986, In: Fairclough, 1992). This includes the different narrative, visual, written and verbal genres present in discourse.

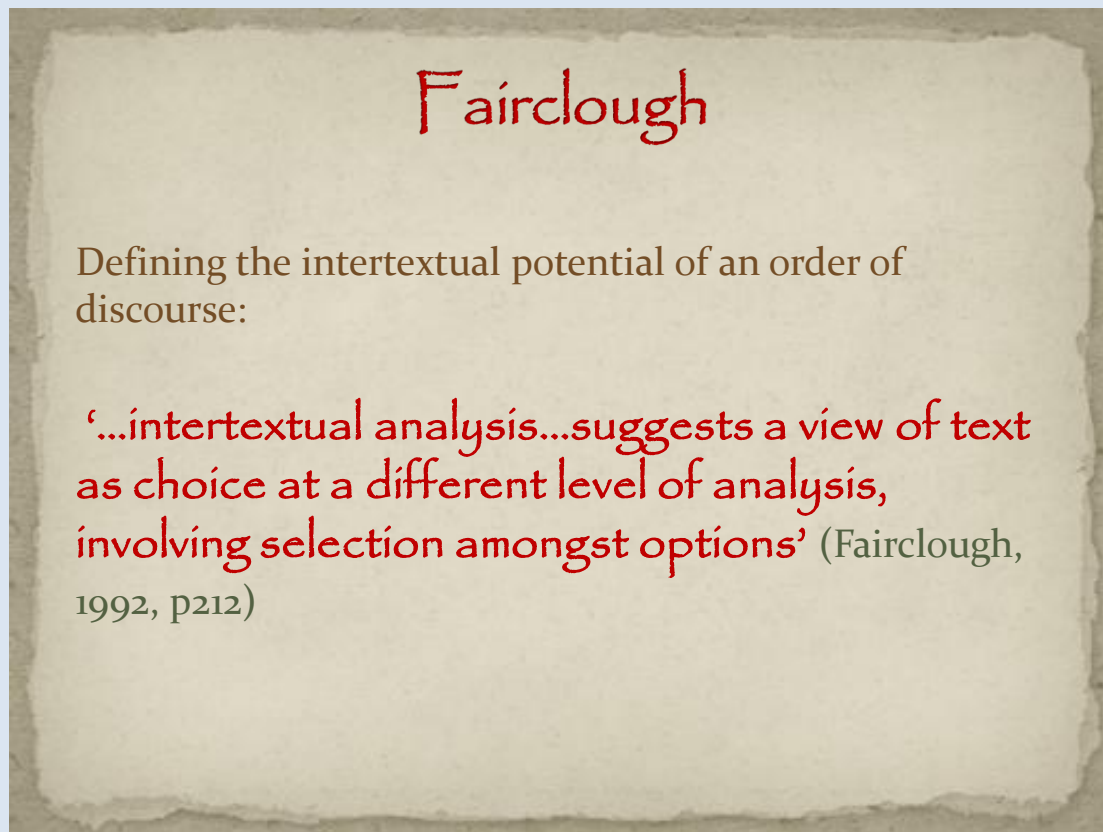


Figure 21: Fairclough and intertextual analysis

This view of intertextual analysis stresses the availability of options regarding the content of meaning-making, which can be analysed at different levels. This perspective supports the view that language and genres of discourse in the hands of non-autistic 'experts' can be incredibly powerful, and ultimately destructive if they miscomprehend and distort autistic perspectives (Beardon and Edmonds, 2007; Beresford, 2005; Milton, 2011b; Milton and Moon, 2012; Parson, 2014). Fairclough (1992) observed that one manifestation of this might be through the discussing

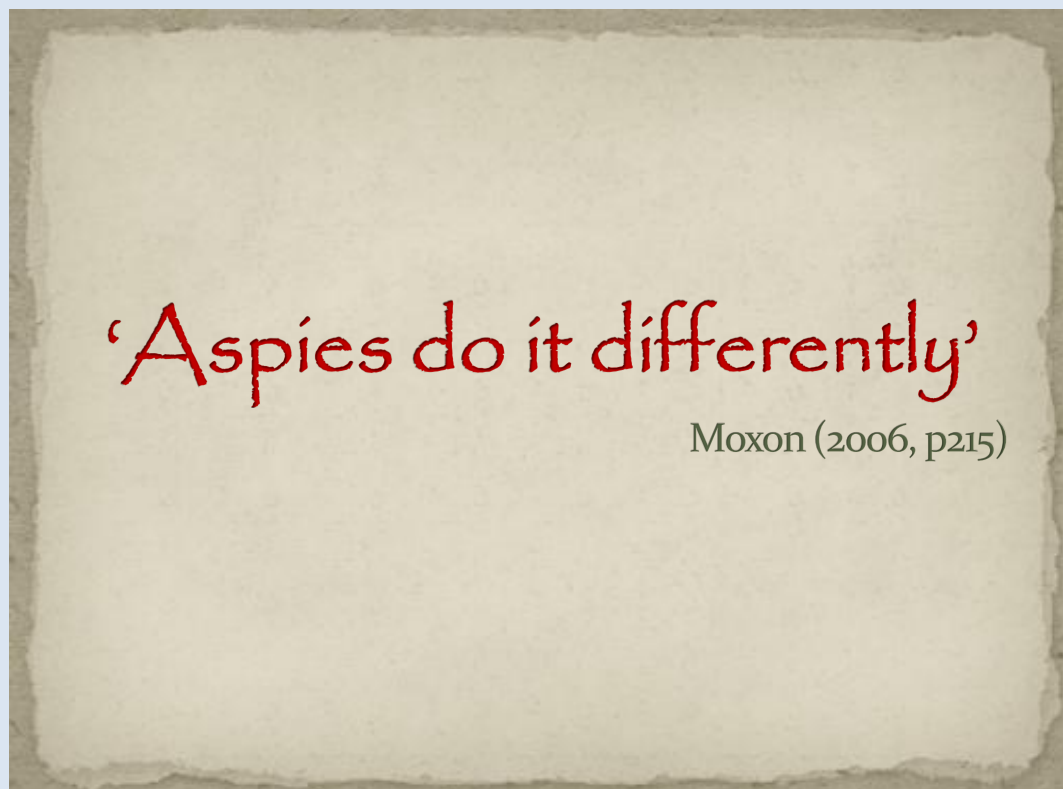
of options included at the expense of ignoring those excluded. In the field of autism, this could be seen as discussing the views of non-autistic experts and ignoring the autistic voice (Graby, 2012; Milton and Bracher, 2013).

The contemporary focus on context as regards CDA is emphasized by van Dijk (2008, p107): the social domains in which discourse occurs, for example education and the media; global social actions such as legislation being impacted on and shaped by discourse; the make-up of participants involved in discursive events; and their beliefs and aspirations. Furthermore, van Dijk (2008, p99) raises the question of adaptability of discourse to other domains, since 'power and dominance are associated with specific social domains'.

CDA in relation to autism focuses on choice of language used by those in power and the contexts in which this is used, as may be evidenced in clinical or educational settings (Attwood, 2000; Baron-Cohen, 2000; Baron-Cohen et al., 1985a; Happe, 1991; Happe' and Frith, 2006). This is in opposition to a power shift towards autistic individuals, listening to the language and terminology many prefer to use to describe their own lived experiences (aspie rhetor, 2015; Baggs, 2003; Connor, 2013; Jackson, 2002; Lawson, 2008a; Murray, 2006b; Robertson, 2010a; Sainsbury, 2009; Simone, 2010b; Walker, 2014). This point acknowledges a dialectical relationship between discourse and power, where power and knowledge are employed as tools of social control (van

Dijk, 2008, p99). Furthermore, it highlights the tension raised by the Foucauldian argument that discourse is characterised by rules of regulation, which are also its constraints regarding 'validity, context and appropriateness of circulation and whose voice is heard' (Simons, 1995, p24).

Autistic narratives increasingly highlight diversity and difference, and these clash with those that only appreciate a single identity (autism), where autistic people fall prey to oppressive processes (Harris, 2015). Aspirations held by autistics regarding education, employment and independent living still remain of lesser value in today's society (Beardon et al., 2009; Hotham-Gough, 2013; NAS, 2011a; Wallis, 2012), and autistic people forced to 'come out' in order to have their support requirements addressed continue to experience inequalities in all areas.



The formation of identities as discussed in the previous section is a complex process (Bagatell, 2007), and the work of Bornstein (2013) advances this debate as it highlights the intersectionality of spaces of regulation, or identities, that may impact on individuals:

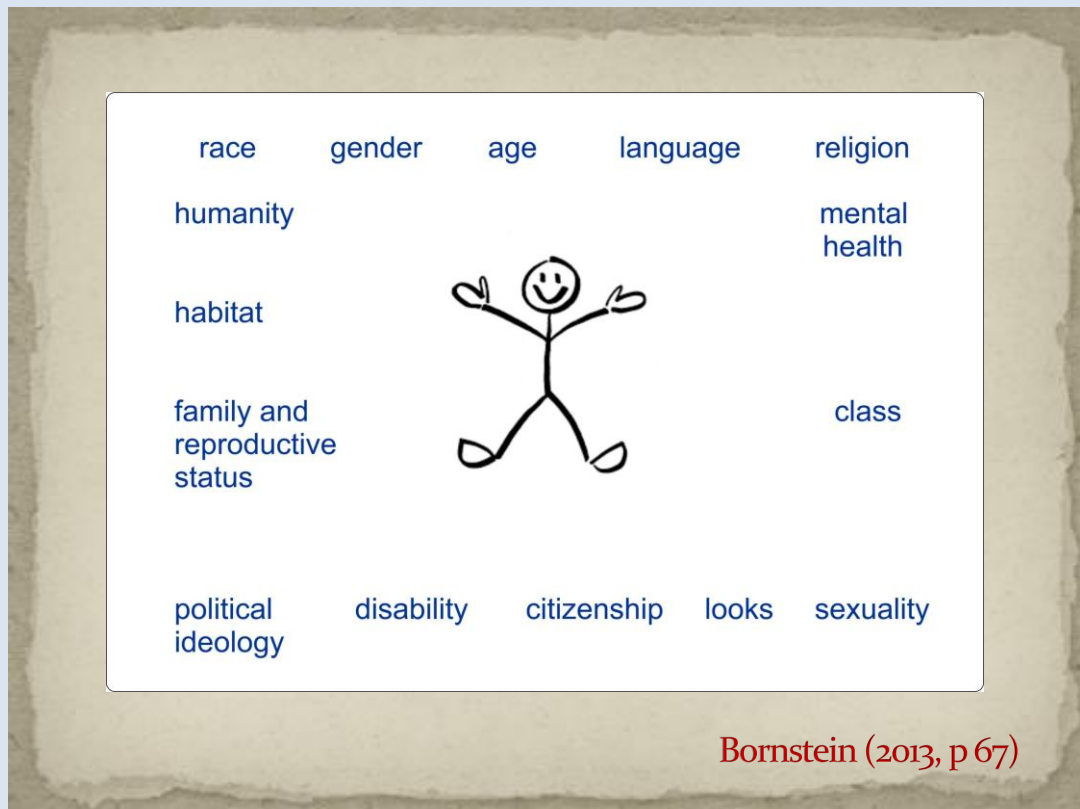


Figure 22: Intersectionality

Pressures to conform to stereotypes are encompassed in discourse around intersectionality, which concerns systems of oppression, domination or discrimination and emphasizes ways in which marginalised groups come together to strengthen their voice (Crenshaw, 1991; Yuval-Davis, 2007). However, identity formation pushes cultural boundaries, and art by autistic/neurodivergent individuals is increasingly used as a means to explore and express themselves (autisticinnerspace, 2015; Murray, 2013; Ridout, 2013c; 2014d).

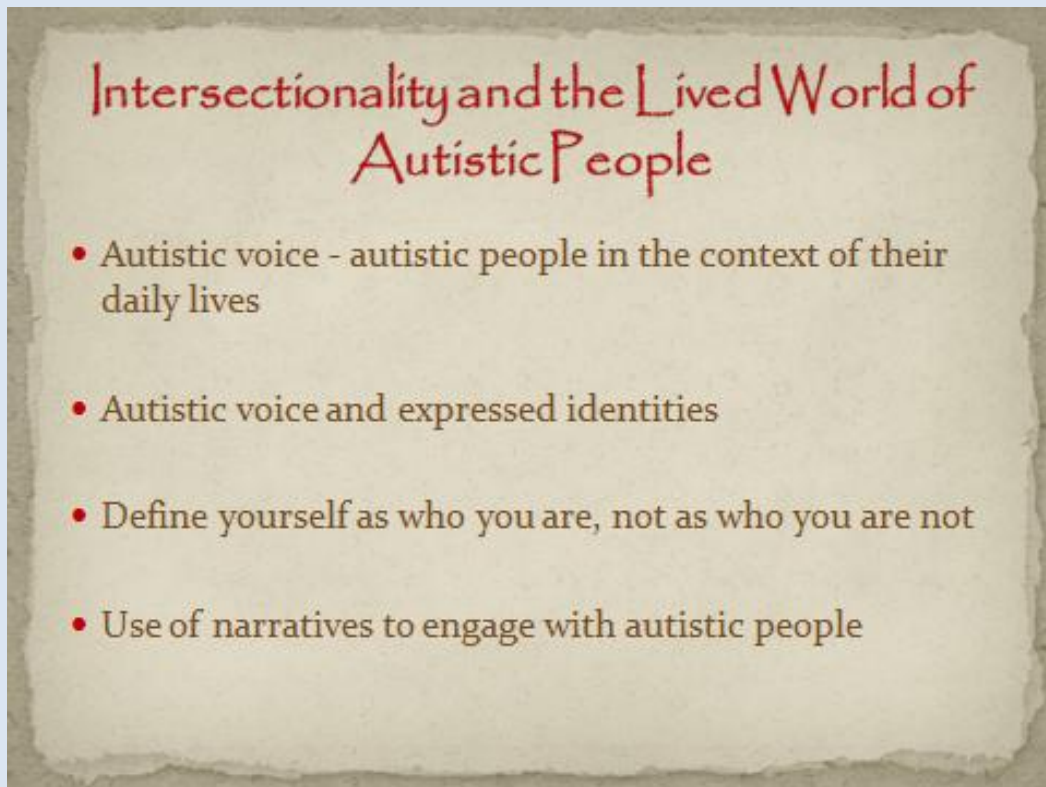


Figure 23: Intersectionality and autism (author's summary)

Intersectionality is a key factor in the autism debate. Autistic people want to be seen and have their voices heard in the context of their diverse and real lived experiences (Grandin, 1995; Grandin and Barron, 2005; Jackson, 2002; Milton and Bracher, 2013; Simone, 2010b; Williams, 2006; 2007). Therefore, it is essential that the narratives reflect the various contexts in which autistic individuals live. Rather than defining oneself as '*who we are not*', opportunity to define oneself '*as who we are*' tackles institutional definitions and identities (Giles, 2013; Graby, 2012; O'Neil, 2008). Furthermore, engaging with autistic narratives in their range of genres opens up possibilities for meaningful dialogue.

The consequences of intersectionality impact at both an individual and a group level, and work by Davis (2008) explored the interaction of multiple identities and experiences of exclusion, subordination and power:

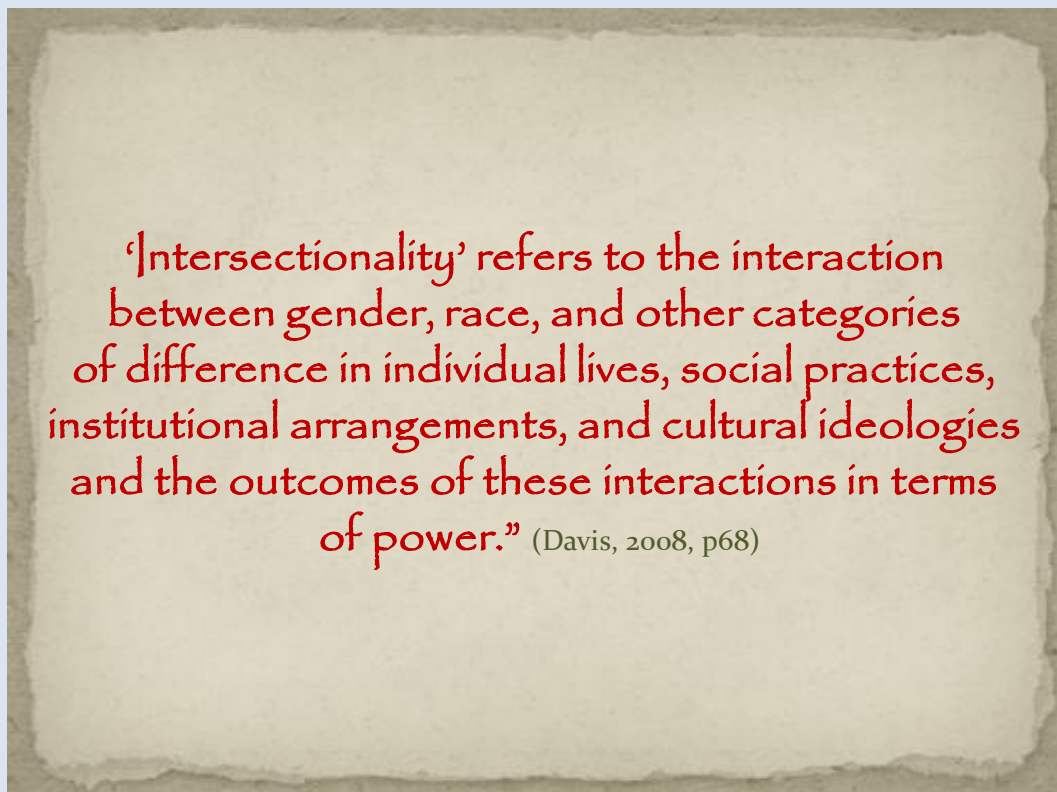
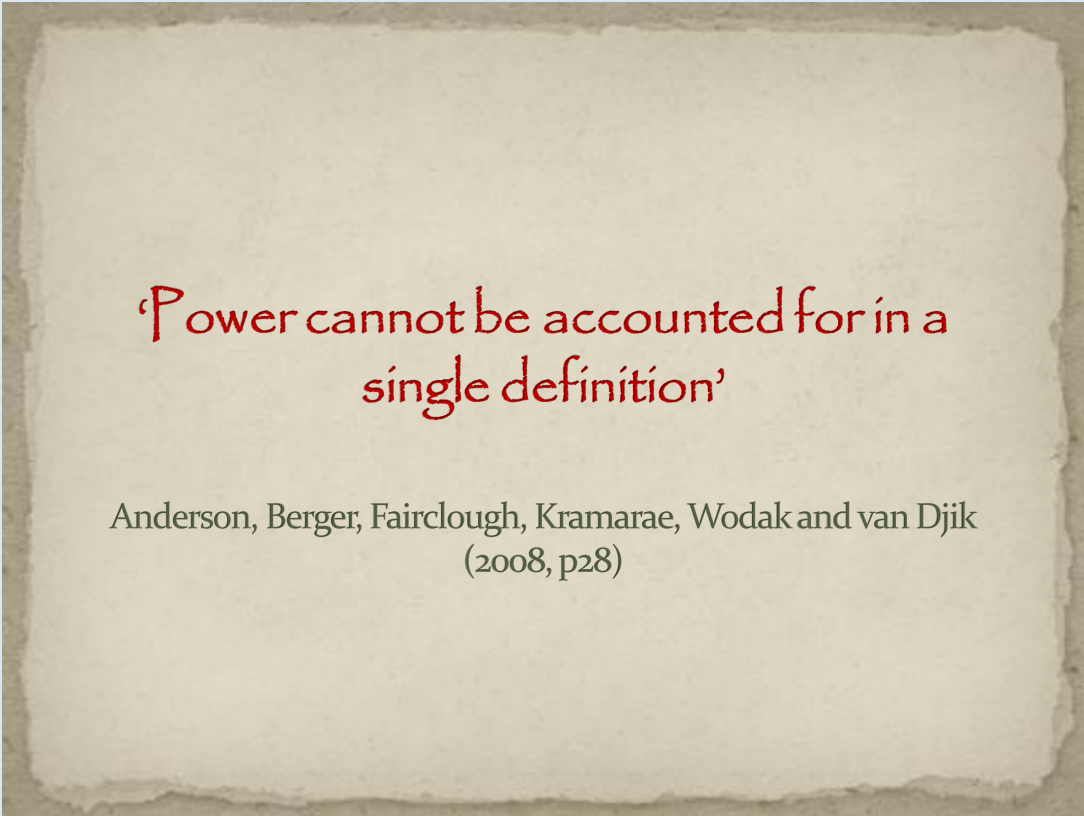


Figure 24: Definition of intersectionality

Autistic individuals frequently voice that among non-autistic practitioners, educationalists and employers there is little attempt to consider the autistic agenda as defined by intersectionality (Graby, 2012; Lawson, 2006a). This can be linked to the majority of approaches to autism espoused by a range of theorists (Section 3.1).



**'Power cannot be accounted for in a
single definition'**

Anderson, Berger, Fairclough, Kramarae, Wodak and van Dijk
(2008, p28)

Definitions of power are numerous and varied, with much disagreement (Lukes, 2005, p61). In 1960, Talcott Parsons defined power as the: "generalised capacity of a social system to get things done in the interest of collective goals" (Parsons, 1963). However, others such as Corbett (1996) place an alternative emphasis on discourse by focusing on 'the language of empowerment'. Perhaps unsurprisingly, this has led to some debate focusing on a possible confusion between 'power' and 'empowerment' (Tew, 2006). Furthermore, in discussing Foucault's position, Simons (1995, p27) observes that power and knowledge 'directly imply each other'. One means of expressing this power is through resistance (Foucault, 1978), and this may emerge in the guise of silence either at an individual or a community level:

“Where there is power, there is resistance.”

Foucault (1978, Vol 1, p95)

“There is not one but many silences, and they are an integral part of the strategies that underlie and permeate discourses.”


Foucault (1978, Vol 1, p 27)

Silence and resistance also inform my study since they characterise the way in which the autistic voice has been excluded in matters pertaining to autism. Whilst the autistic voice may have been excluded from public discourse and traditionally silenced in research, except on a participatory level (Milton and Bracher, 2013; Moon, 2014c), online communities and autistic-led organisations have developed (ANI, 2000; ARGH, 2014; ARM, 2010; ASAN, 2014; Autscape, 2013; Wrong Planet, 2004). Furthermore, resistance is taking shape as an increasing number of autistic narratives emerge (Baggs, 2003; Baggs, 2013; Holliday-Willey, 2006; Jackson, 2006; Jackson, 2002; Lawson, 2006a; Sainsbury, 2009; Yergeau, 2010; 2013).



Figure 25: Impact of context and power (author's summary)

A critical aspect of my study is to highlight a requirement for all engaged in autism research to address the issue of power from a range of perspectives, acknowledging its very real impact on the lives of individuals, communities and services (DoH, 2010a; HMSO, 2010; NICE, 2010; UN, 2006). Context impacts on narratives and narrative layers (de Fina, 2011; Glasby and Tew, 2015; Taylor, 2006), and the shifting of power has a profound impact on the lives of autistic people:

A quote is presented on a rectangular piece of aged, yellowish-brown paper with a rough, torn edge. The paper is centered on a light blue background. The text is written in a red, serif font and is arranged in four lines.

‘Participation and inclusion
are significant steps forwards
from ‘having things done to
us’’

Dunn (2014b)

Perhaps one of the trickiest questions pertaining to service delivery concerns processes of oppression and empowerment, which relate directly to any discourse occurring throughout service development and improvement (Charlton, 2000; Tew, 2006). Charlton (2000, p5) argues that the ‘*Nothing About Us Without Us*’ approach provides an essential ‘epistemological break with previous thinking about disability’ that ‘forces disabled people into cycles of dependency’. Additionally, Charlton argues for the recognition of the individual nature of disabled people’s experiences and the generalisable collective experiences and resistance to oppression. This sits within the social model of disability, with systems and attitudes seen as the disabling factors resulting in unhealthy cycles of dependency and the devaluing and deskilling of individuals (Glasby and Tew, 2015, p63).

A conceptual matrix proposed by Tew (2006, p7) responds to attitudes within social work, but can be equally applied across many services. This framework aims to address fluid identities and 'locate different possibilities of power'. A distinction made between 'the vertical operation of power over' occurring where there are social differences or divisions, and 'the horizontal development of power together between people', places an emphasis on the division between power as a limiting or facilitating tool.

	Power over	Power together
Productive modes of power	Protective Power Deploying power in order to safeguard vulnerable people and their possibilities for advancement	Co-operative Power Collective action, sharing, mutual support and challenge – through valuing commonality and difference
Limiting modes of power	Oppressive Power Exploiting differences to enhance own position and resources at the expense of others	Collusive Power Banding together to exclude or suppress 'otherness' whether internal or external

Tew (2006, p8)

Figure 26: Conceptual matrix to locate power

In terms of autism research, previous work by practitioners and researchers have placed autistic people's lived experiences in the matrix cells delineated by Protective Power, Oppressive Power and Collusive Power (see Sections 3.1 and 3.2). These cells highlight how power

wielded by non-autistic others may have denied many autistic people their equal rights (ARGH, 2014; UNCRPD, 2006) and access to opportunities, causing distress and increased dependency by deskilling and disenfranchisement (Beardon et al., 2009; Beardon and Worton, 2011; Harris, 2015; Lawson, 2001; 2011; Milton and Moon, 2012; Ridout et al., 2011).

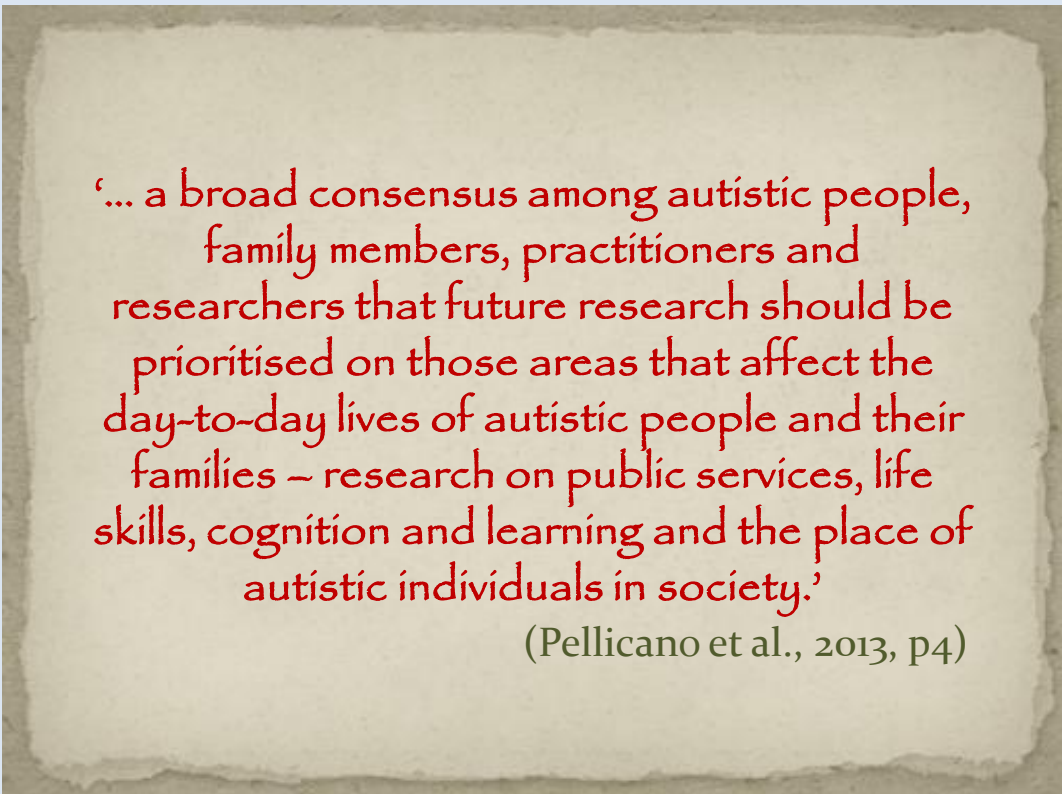
The cell relating to oppressive power is one which I consider best emphasizes the experiences of autistic individuals, who are not 'easily able to compartmentalise' and have been denied access to services because 'they did not fit requirements' (Ridout et al., 2011). In addition, in some cases, this reflects incidents of a serious lack of care (Ryan and Ryan's blog: <https://107daysofaction.wordpress.com/>). Frequently, there seems to have been little attempt at understanding the everyday impact of sensory and social overload or social exclusion (Bogdashina, 2003; Jackson, 2004; Jackson, 2002; Lawson, 2001; 2011; Simone, 2010b), and internalised frustration has in many cases led to mental distress (Andrews, 2006; Beresford and Boxall, 2013; Berney, 2006; Dawson, 2006).

The lived experiences of many autistic individuals have now resulted in a backlash, placing discourse in the cell relating to Collusive Power as autistic voices began to speak out (Arnold, 2012; aspie rhetor, 2015; Grandin, 1995; 2009; Grandin and Barron, 2005; Jackson, 2004; 2006; Jackson, 2002; Lawson, 2001; 2003; 2005; 2006a; b; Lawson, 2008a;

Lawson, 2008b; 2010; 2011; Moon, 2014a; c; Murray and Lesser, 2006; Murray et al., 2005; Sainsbury, 2009; Shore, 2006; 2008; Simone, 2010a; b; Simone, 2014; Sinclair, 1992; 2012; Tammatt, 2009; Williams, 1999a; b; Yergeau, 2010). However, it is worth reiterating that although autistics are speaking out increasingly, they are still not being listened to or included in 'processes of knowledge production' about autism (Milton and Bracher, 2013).

By including autistic people's narratives of their experiences, this agenda with a subsequent shift in power can be addressed. This would straddle the cells of collusive power and co-operative power unless all parties agree to a collaborative approach. One example of this power shift occurred in 2014, as the UK saw its first autistic-led conference, Autism and Participation, established by the NAS and a project that it funded called Ask Autism (NAS and Ask Autism, 2014). The conference was refreshing in that it was shaped and delivered, aside from one of the introductory speeches, by autistic people in the UK. Consequently, a very different tone was established to that of typical autism conferences, and one that did not 'wheel out' individual autistic people to talk about past bad experiences in a form that has been called 'fishbowling' (Moon, 2014c).

A further power shift has arisen in relation to the future focus of research, and raised in the publication of *A Future Made Together: Shaping autism research in the UK* (Pellicano et al., 2013), which points to:



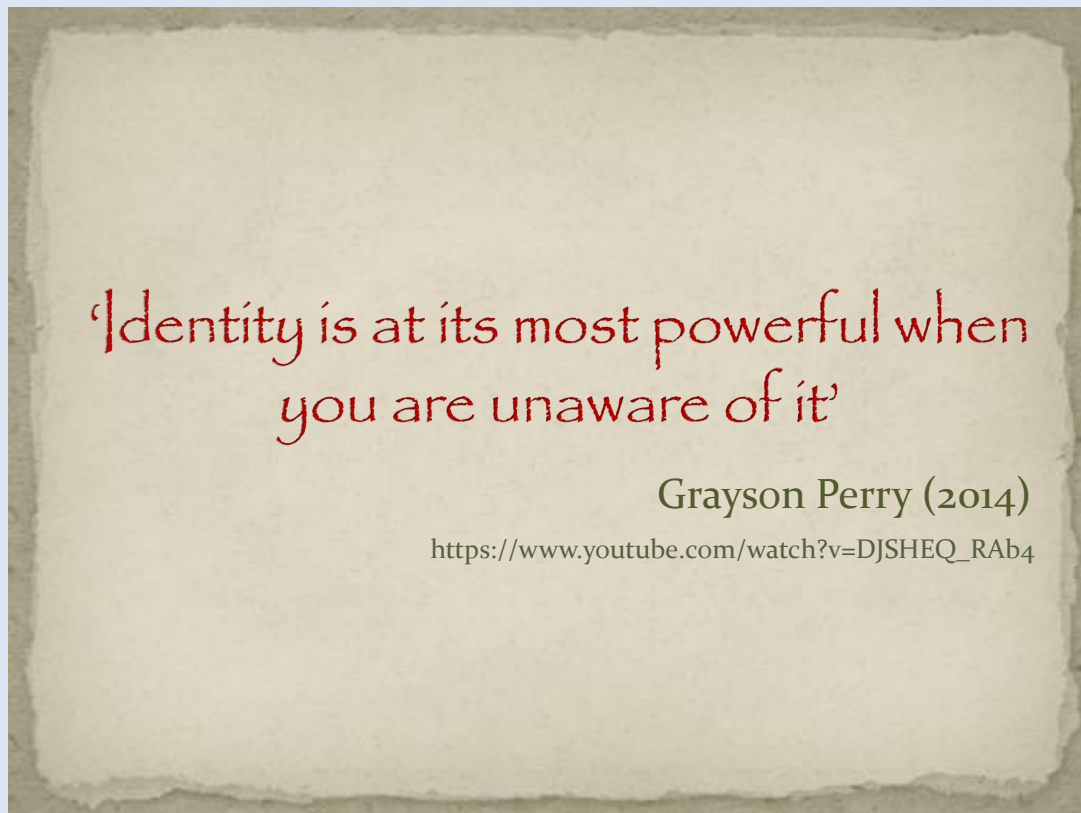
‘... a broad consensus among autistic people, family members, practitioners and researchers that future research should be prioritised on those areas that affect the day-to-day lives of autistic people and their families – research on public services, life skills, cognition and learning and the place of autistic individuals in society.’

(Pellicano et al., 2013, p4)

The establishing of the Theorising Autism Project by a group of autistic and neurodivergent individuals in the UK demonstrates attempts to reframe autism. The initial workshop addressed education (TAP, 2012), and was followed by a second to explore Shaping Research Together (TAP, 2014). The project, still in its infancy, aims to bring together those interested in autism to discuss issues relevant to the everyday lives of autistic/neurodivergent individuals and to scrutinise how certain practices can limit or open up opportunities for us (Greenstein, 2014; Ridout, 2014d).

So it can be surmised that the interrelationship between fluid identities, diverse contexts and power is not a simplistic matter for debate as it

depends on many variables. A powerful contemporary figure, albeit non-autistic, argues about the possible impact of identity:



This raises the question as to whether it works to the advantage of autistic individuals to engage in compartmentalisation according to traditional practices established under the medical model of disability, for it is this that delimits skills and imposes fixed identities (Gilchrist et al., 2010, p21).



Figure 27: Defining autistic identity (author's summary)

Nevertheless, what many autistic people consider to be of importance is a sense of 'feeling different' and pressure to accept oneself against some 'norm' (Milton and Moon, 2012; Reeve, 2002; Reeve, 2004). It would appear that there is a call for discourse and opportunities to facilitate coming out in its various guises, looking at the fluid individual and collective agendas presented. Increasingly autistic activists are challenging perceived social norms, thereby placing themselves as 'irreverent observers' or deviants (Becker, 1991).

Having reviewed literature to explore ways in which identity, context and power inter-relate, the next part of this section explores issues relating to wellbeing.

4.2 Wellbeing

I now review the main distinction in current wellbeing debates and discuss how, rather than focusing on what is problematic in the lives of autistic individuals, a shift in attention can perhaps be more useful in considering the wellbeing of autistic individuals.

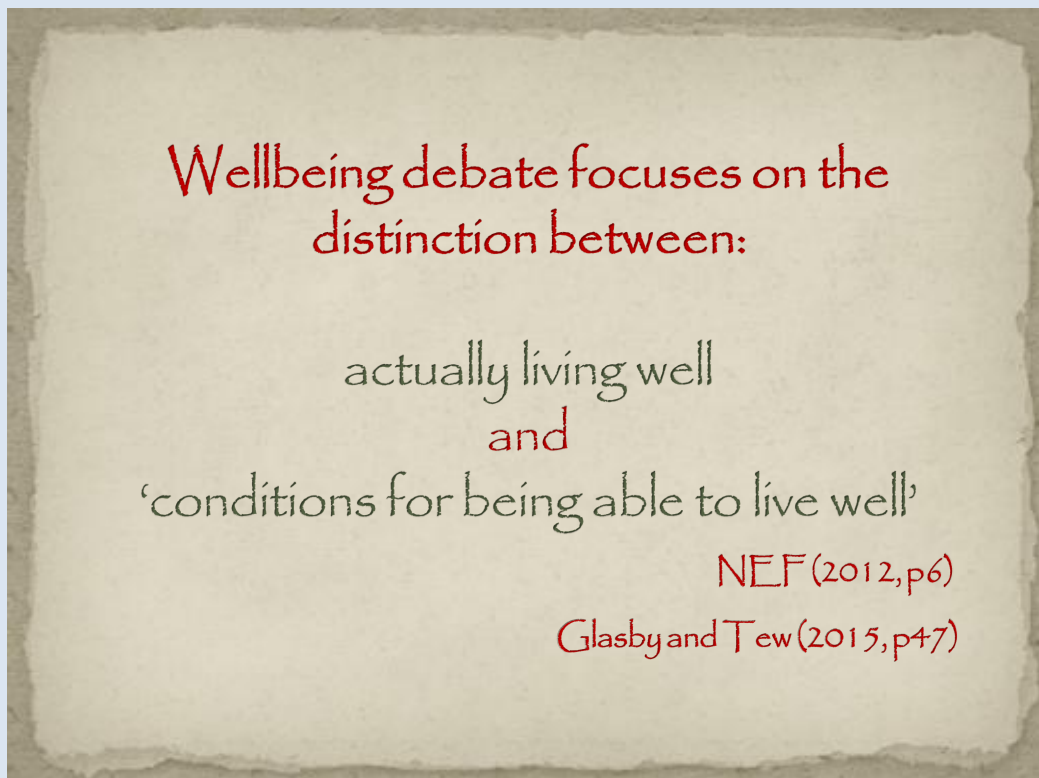


Figure 28: Wellbeing focus

Although the definition of wellbeing remains a contested issue, it has a general focus on the quality of people's lives (Rees et al., 2010). For the purposes of my study, I draw together the components proposed by Seligman (2011) and the New Economics Foundation (NEF (2012) to define wellbeing as they provide a lens with a positive focus. Seligman (2011) identifies factors integral to wellbeing under the acronym PERMA: **P**ositive emotions, **E**ngagement (flow), **R**elationships/social connections,

Meaning and purpose and **A**ccomplishment, and those constituents named by the NEF (2012, p30) relate to: emotional wellbeing, a satisfying life, vitality, resilience and self-esteem and positive functioning.

Important to my study, where I explore individual experiences, Steptoe et al. (2014, p61489) describe subjective wellbeing, which consists of three components, namely: evaluative wellbeing (life satisfaction), hedonic wellbeing (feelings of happiness, sadness, anger, stress, and pain), which declines with age (NEF, 2012; Weich et al., 2011) and eudemonic wellbeing (sense of purpose and meaning in life), which is higher in women, increases in age and is more adversely impacted on by unemployment (Weich et al., 2011). Wellbeing is increasingly referenced within health promotion (Seedhouse, 1997; Steptoe et al., 2014), impacting on policy and practice. Traditional measures of psychological wellbeing have focused on an absence of positive mood, or low hedonic wellbeing (de Chavez et al., 2005) and philosophical debate has separated hedonic and eudemonic components (Henderson and Knight, 2012). However, contemporary practice within the fields of mental health and psychology emphasises their distinct yet complimentary features, and there is now recognition of their combined effect, namely 'flourishing' (Glasby and Tew, 2015; Henderson and Knight, 2012). How these two components manifest themselves throughout the lives of autistic individuals is critical to understand in terms of establishing appropriate services and is key to my study debate.

Hedonic wellbeing and autism

Factors which one might expect to fall under this heading concern engagement in interests, being satisfied with work (education or employment), and happiness with life in general as well as having a sense of belonging and a purpose in life. Whilst many autistic people relish time to themselves (Calder et al., 2013), this needs to be understood in context. Reports of low hedonic wellbeing among autistics are high as their expressed feelings of isolation and barriers to contributing to their community impact negatively on the development of a sense of purpose in their lives (Beardon and Worton, 2011, p103; Milton and Moon, 2012). Many autistic people voice dissatisfaction with support within education (Beardon and Edmonds, 2007; Knott and Taylor, 2014) and work satisfaction is also reportedly low, with issues of reasonable adjustments at all stages of the employment process being left unattended (Beardon and Edmonds, 2007; Billstedt et al., 2011). Consequently, unemployment and underemployment remain high among autistic people (Allard, 2009; Hotham-Gough, 2013; Rosenblatt, 2008) impacting further on opportunities for independent living.

Eudaemonic wellbeing and autism

In the light of studies of autistic people, and perhaps more importantly, their own narratives, eudaemonic wellbeing might be potentially less apparent due to reduced opportunities for autistic people to form friendships and relationships (Brown, 2008; Garvey, 2008; Howard et al.,

2006; Lawson, 2003). This is apart from online forums and chat rooms and the previously mentioned handful of autistic-led conferences (ASAN, 2014; Autscope, 2013; Sinclair, 2005). Barriers to exercising agency and choice become evident when we consider opportunities experienced by autistic people to express themselves and be heard (Milton and Bracher, 2013).

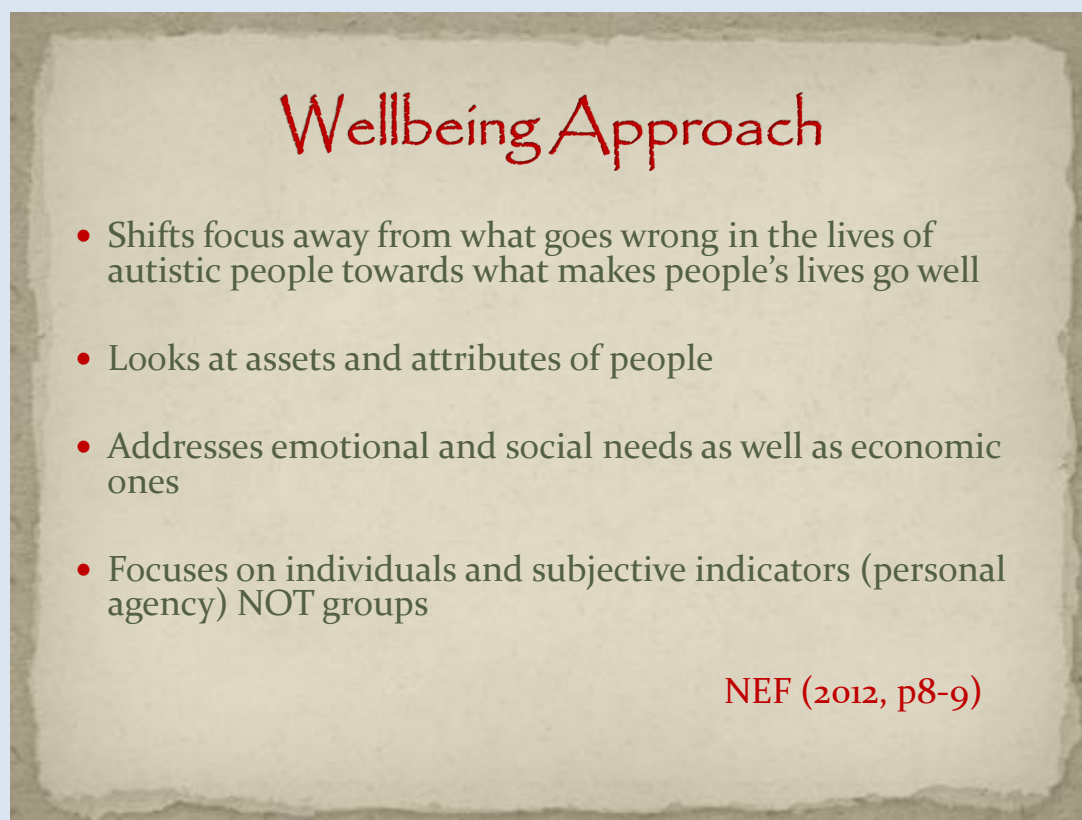
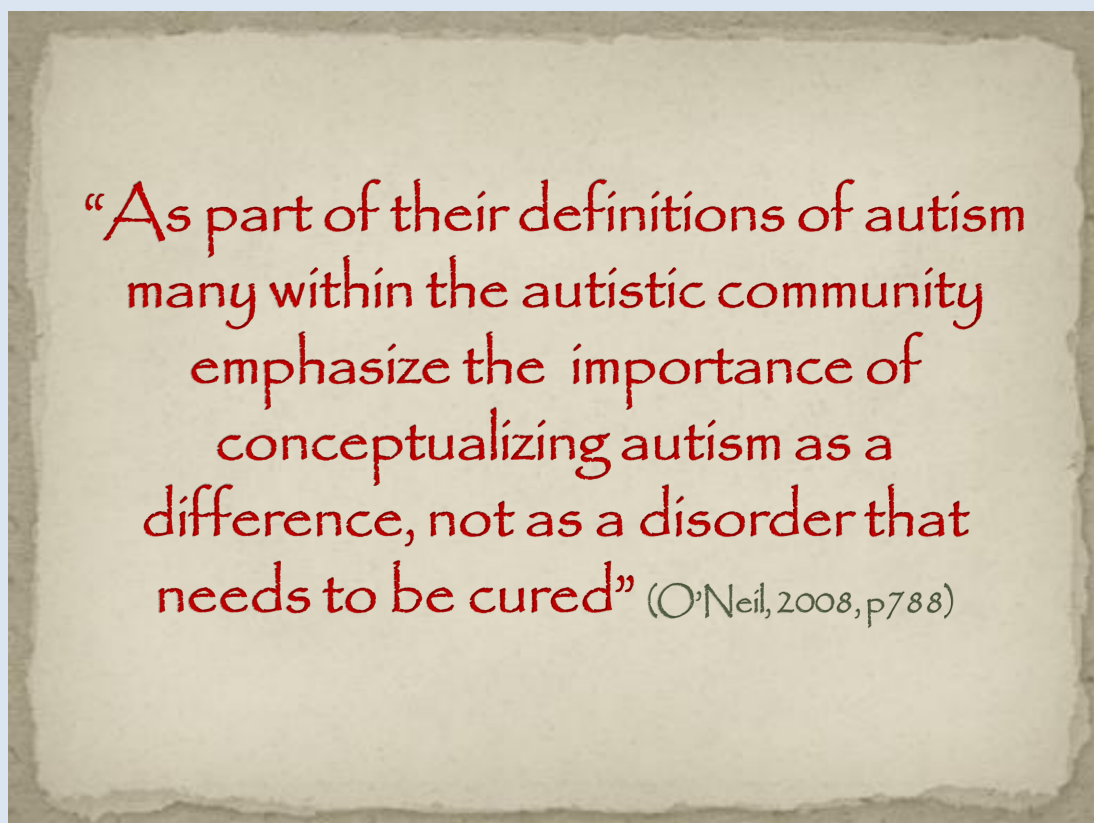


Figure 29: Wellbeing approach

The perspective on health provided by a wellbeing approach is a wider focus on aspects that 'make people's lives go well' (NEF, 2012), supporting the view proposed by many health promotion practitioners (Ewles and Simnett, 1996, p20; Naidoo and Wills, 1998; Seedhouse, 1997). At its core is a shift in focus, away from the negative things

impacting on people, or 'conditions for being able to live well', such as a lack of decent housing or employment, and towards an emphasis on the skills and positive attributes individuals can bring to a situation (NEF, 2012). In fact, the autistic voice on differences in the ways autistic and neurodivergent individuals think, feel, behave and function fits well with the mental wellbeing checklist proposed by the National Mental Health Development Unit, which emphasises wellbeing in relation to both the individual and the community (Baggs, 2003; Harris, 2015; Lawson, 2001; 2006b; NMHDU, 2010b; Robertson, 2010a; Yergeau, 2013).



The conceptualisation of autism as a difference is important to my study. It impacts on autistic individuals' wellbeing and acknowledges their skills, knowledge and abilities, reflecting the voice of many autistics (Chown and

Beavan, 2012; O'Neil, 2008). Linked to this is the neurodiversity perspective, which 'describes the neurology and personhood of autistic people through the lens of human diversity' (Harris, 2015; Milton and Moon, 2012; Robertson, 2010a). Furthermore, many individuals enjoy being autistic as it is an integral part of them, and one from which they cannot be separated...a fact which flies in the face of the position promoted by medical model enthusiasts (Connor, 2013; Sinclair, 1993; 2007). Another example of this comes from an autistic artist, who comments: 'the autistic mind is a wonderful attribute and autistic individuals should be loved and treasured', and her artwork reflects this belief (autisticinnerspace, 2015). From this perspective, it is evident that autistic people are able to flourish.

The potential drivers for wellbeing, as illustrated by the NEF (2012) dynamic model of wellbeing below, focus on skills and attributes found in the personal resources of an individual and the external conditions within which they function:

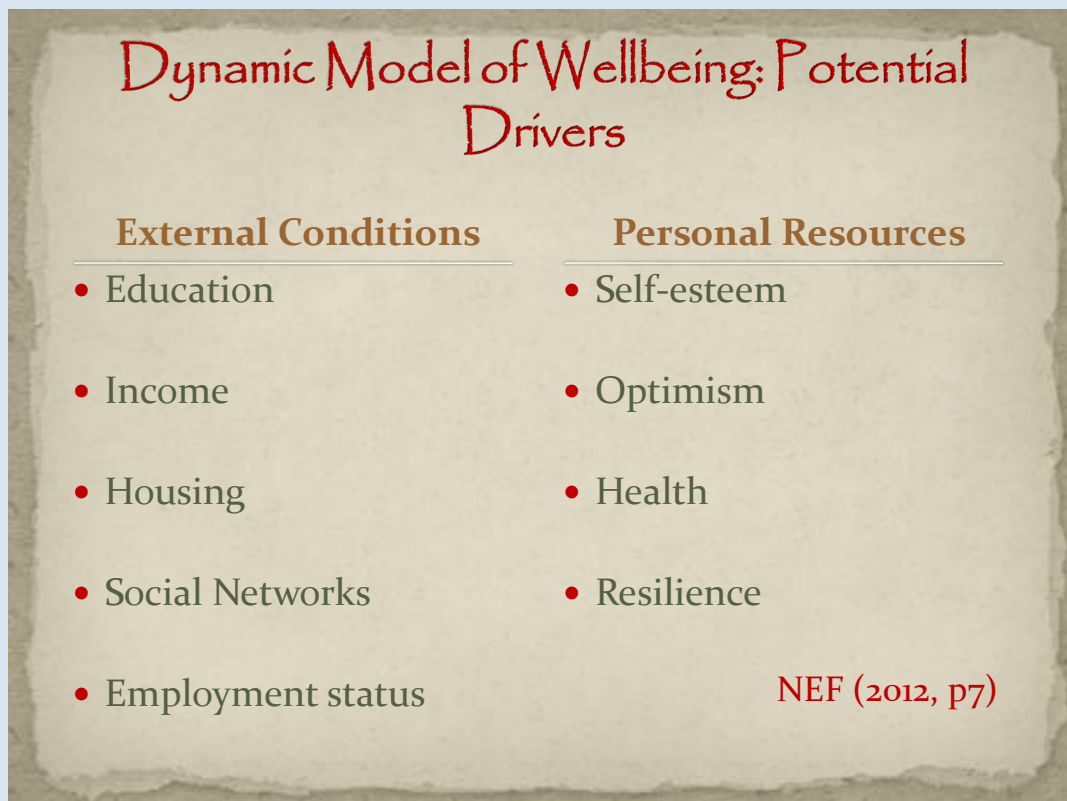


Figure 30: Dynamic model of wellbeing – potential drivers

When linked to the literature on the autistic voice on quality of life, an overview of these drivers highlights the fact that, although some autistic people do have a sense of personal agency in matters concerning them (eudaemonic wellbeing), there remain considerable barriers to many achieving quality of life (Chown and Beavan, 2012; Grandin, 1995; Robertson, 2010b; Yates and Roulstone, 2013). For the most part, autistic people are underemployed or unemployed (NAS, 2011b), have unequal access to quality housing, remain inappropriately supported within employment and at all levels of the education system (Beardon and Edmonds, 2007; Beardon et al., 2009). As a result, many are likely to experience poor self-esteem and overall health, be less resilient and

increasingly less optimistic as regards future opportunities (Andrews, 2006; Beardon and Worton, 2011; Meyerding, 2006).

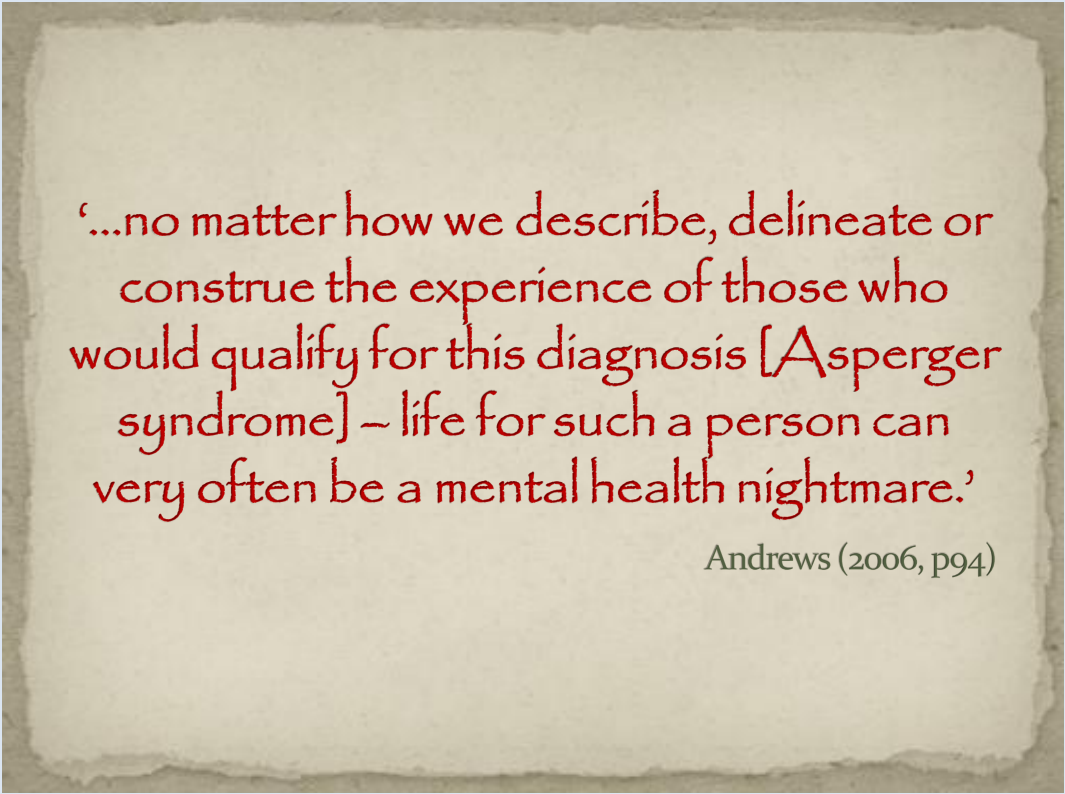
In relation to my study, the notion of collaborative partnerships offered by the wellbeing approach, such as those between autistic people and service providers, is key to addressing barriers in the way of inclusion of autistic individuals and facilitating a process whereby they might realise their full potential (AASPIRE, 2015; ASAN, 2014; Nicolaidis et al., 2012). Autistic individuals may well have established a number of compensatory strategies or skills, and inclusion of the user [autistic] voice on service provision may be invaluable to creating more appropriate and accessible services (Beresford, 2002; Glasby and Tew, 2015; Robertson, 2010a).

The mental wellbeing checklist (below) (NMH DU, 2010b), also supported by Coggins (2011), is another critical aspect to factor into the wider debate on wellbeing as it acknowledges aspects impacting at an individual and a community level:



Figure 31: Mental wellbeing checklist

Despite this checklist, the conditions for wellbeing go largely unattended. The autistic voice on wellbeing currently speaks to an agenda comprising a majority of outsider voices characterised in many cases by negative assumptions and a lack of focus on abilities. Several key rights for disabled people (UNCRC, 2006) remain unaddressed, such as those specifically concerning: respect for dignity, autonomy and independence, non-discrimination, a right to participate fully and effectively in society and a respect for differences (Robertson, 2010b). Consequently, the mental health nightmare (described below) is an experience not atypical among autistics, and reflects the stripping away of any qualifications, skills or identities (Andrews, 2006; Murray, 2006a):

A quote is presented on a rectangular piece of aged, yellowish-brown paper with irregular, torn edges. The paper is set against a light blue background. The text is written in a red, serif font and is centered on the paper.

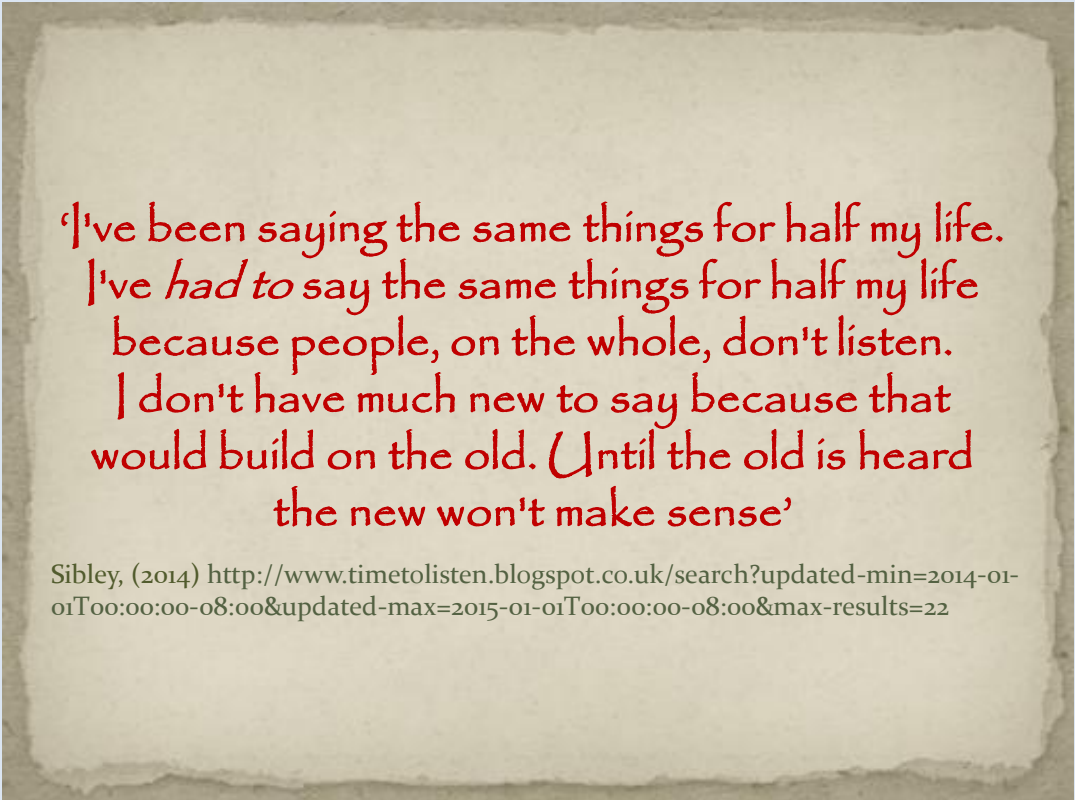
‘...no matter how we describe, delineate or
construe the experience of those who
would qualify for this diagnosis [Asperger
syndrome] – life for such a person can
very often be a mental health nightmare.’

Andrews (2006, p94)

Negative assumptions embedded in many autism theories (Baron-Cohen et al., 1985a; Frith and Happe, 1994; Happe’ and Frith, 2006) have introduced a storyline of dysfunction adversely impacting on the self-esteem of numerous autistics. This narrative is being increasingly challenged by autistic writers and researchers, who offer alternative explanations relating to their real lived worlds (Milton, 2011a; Murray et al., 2005) and which address more than the singular identity of ‘autistic’ (Bagatell, 2007). Autism seen as a disorder, which is the focus of traditional autism theories aiming to reshape autistic behaviour to fit society’s expectations, has had a damaging impact on the lives of numerous autistic individuals (Andrews, 2006).

Whilst internationally, cultures ponder over whether to perceive autism as naturally occurring human diversity, or as a disease (Broderick and Ne'eman, 2008), the predominance of discriminatory language, describing autism as high-functioning or low-functioning, frequently denies some individuals access to much-needed services (Harris, 2015). In addition, although many consider that the removal of Asperger syndrome from the DSM-V has 'stolen' the autistic identity of numerous individuals (Giles, 2013), the resultant effect has been the splitting of autistic voices. As such, some individuals are content to recognise their newly formed identities as being a 'spectrumite', whilst others choose to stick by their 'aspie' identity. Meanwhile, psychiatric labelling has inevitably stirred discussion (Charland, 2005), and it is this researcher's view that the outsider splitting of autistic communities is an infringement of the rights of autistic people to form their own diverse identities and may further impact on wellbeing.

The influence on wellbeing is further apparent as disenfranchised autistic people are unable to progress their lives as they would wish, both prior to and following diagnosis. In the words of one neurodivergent individual:

A quote is displayed on a rectangular piece of aged, yellowish-brown paper with a rough, torn edge. The paper is centered on a light blue background. The text is written in a red, serif font. The quote is: 'I've been saying the same things for half my life. I've *had to* say the same things for half my life because people, on the whole, don't listen. I don't have much new to say because that would build on the old. Until the old is heard the new won't make sense'.

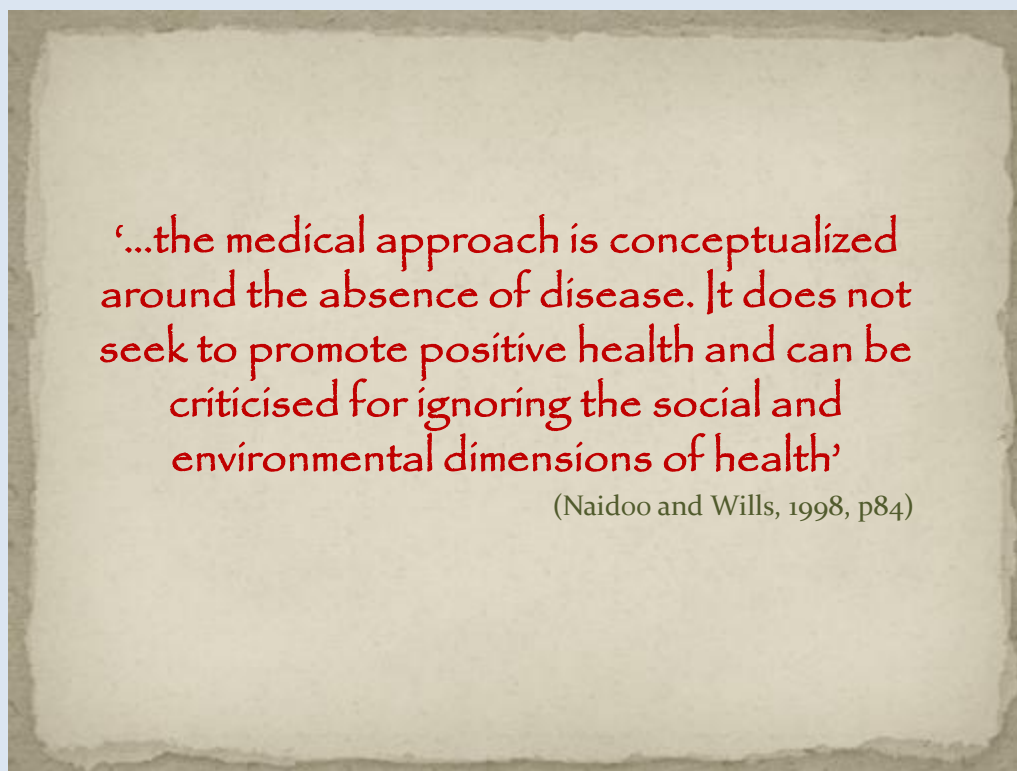
'I've been saying the same things for half my life.
I've *had to* say the same things for half my life
because people, on the whole, don't listen.
I don't have much new to say because that
would build on the old. Until the old is heard
the new won't make sense'

Sibley, (2014) <http://www.timetolisten.blogspot.co.uk/search?updated-min=2014-01-01T00:00:00-08:00&updated-max=2015-01-01T00:00:00-08:00&max-results=22>

Conversation on wellbeing emphasises the identity-diagnosis divide (Harris, 2015), since receipt of a diagnosis, whilst at times bringing a sense of relief, can also be a curse (Andrews, 2006, p97). The pathologising of autism, primarily by non-autistic practitioners keen to diagnose, generally fails to acknowledge other identities and communication preferences of autistic people and can lead to reduced opportunities to engage with others (ANI, 2000; Bagatell, 2007; Chown and Beavan, 2012). This negative impact on wellbeing can also incorporate resultant feelings of loneliness and isolation and low confidence and self-esteem (Andrews, 2006; Milton and Moon, 2012; Müller et al., 2008). Autistic autobiographies emphasise the need for diagnostic practitioners to consider the implications of the diagnosis in the

context of the individual's life (Murray 2006), as wider societal influences may often result in mental health problems (Andrews, 2006).

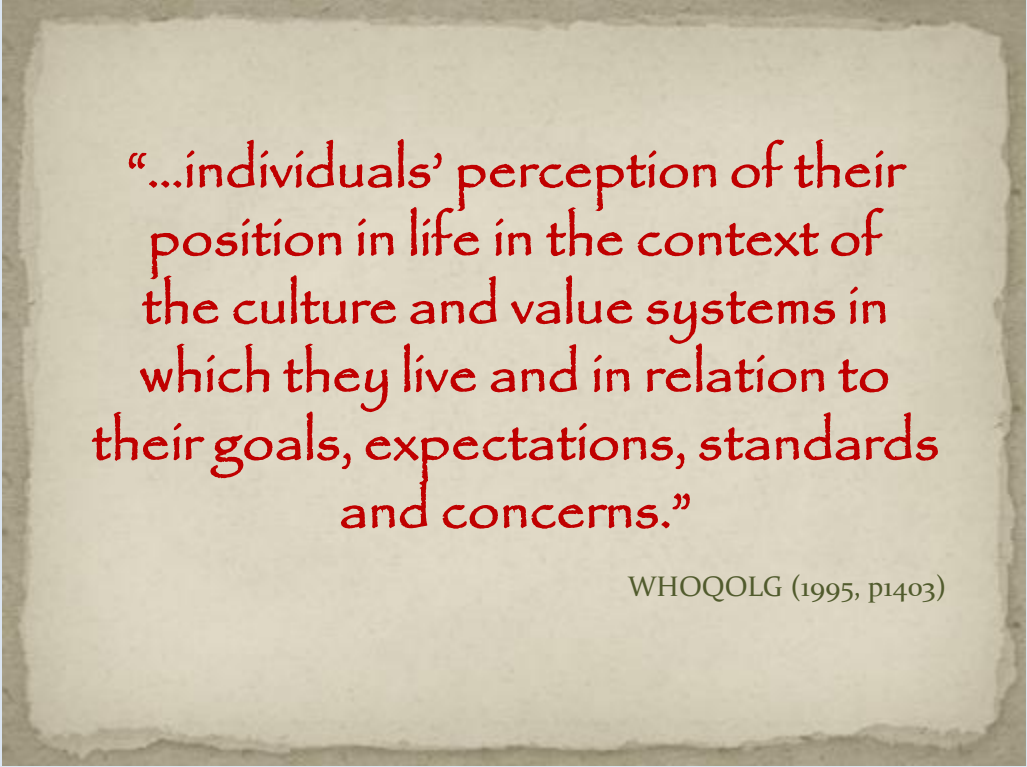
Bagatell's perspective on the challenges of constructing an identity (Bagatell, 2007) is also put forward by autistic individuals in the edited books by Murray (2006a) and Beardon and Worton (2011). These incorporate the varied reactions of autistic people and some practitioners on the issue of diagnosis. Of interest too, is that there are many opponents among the health professions critical of the focus of the medical model and its damaging effect on wellbeing more generally:



Outsider expertise frequently fails to acknowledge and include autistic expertise, and coupled with the imposition of a sole identity, autism, the cumulative effect of this is the stripping away of self-esteem (Andrews,

2006). Reduced social freedom of action through the de-skilling of [autistic] people and compelling societal pressures to conform to imposed social norms (van Dijk, 2008), heightens anxiety among autistic individuals. Furthermore, the denial of skills is argued by some to be a socio-political management strategy, which creates a climate of dependency (van Dijk, 2008, p131). These adverse consequences of context and power on wellbeing have been raised by autistic people (ARGH and HUG, 2011; Shepherd, 2008) as a failure to listen to and understand them and can impact negatively on wellbeing (Beardon and Edmonds, 2007; Beardon and Worton, 2011). A possible result is tokenistic gestures to both inclusion and employment forcing many into benefit dependency (Beardon and Edmonds, 2007; CSCI., 2007; Ridout et al., 2011).

Autistic people have a right to quality of life and wellbeing (UNCRPD, 2006), and so to counteract the imbalance in theories offered to date by non-autistic people, neurodivergent/autistic individuals are formulating their own (Section 3.1) to more accurately reflect their experiences (Lawson, 2011; Milton, 2012a; Murray et al., 2005). As with 'wellbeing', the definition of quality of life is heavily contested, but for the purposes of this study, the World Health Organisation Quality of Life Group (WHOQOLG, 1995) is the working definition employed:



“...individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.”

WHOQOLG (1995, p1403)

Figure 32: WHO Quality of Life Group

As a contribution to the wellbeing approach, the framework introduced by Shallock (2004), recognises its importance regarding service delivery, but a prevailing lack of understanding as to the application of findings of quality of life studies in terms of service improvement. This strikes a chord with quality of life research in relation to autism, since evidence points to a dearth of studies in this area (Robertson, 2010a).



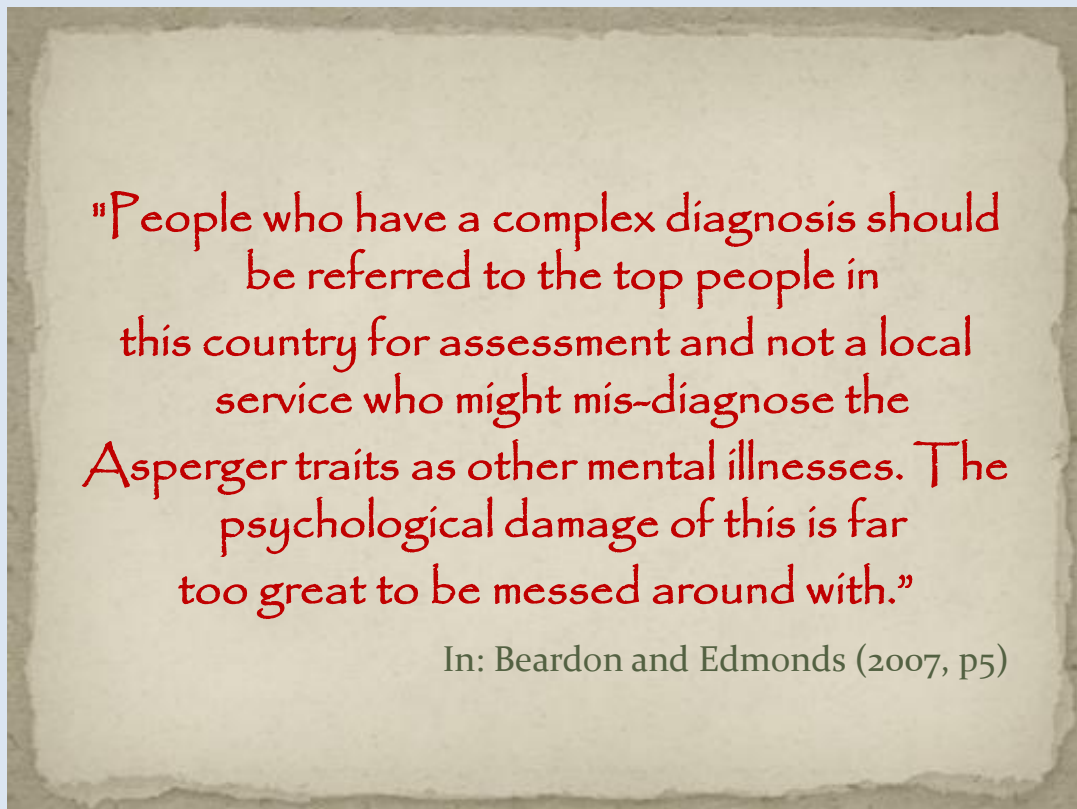
Figure 33: Factors impacting on quality of life (author's summary)

There are several barriers to autistic people attaining quality of life, and recent arguments place increased emphasis on communication differences between autistic and non-autistic individuals (Chown, 2014a; Milton, 2013; Milton and Bracher, 2013). The relationship between psychiatric accounts and life histories, which include first person autistic voices, is now being balanced by emerging [autistic] narratives (Russo and Beresford, 2015). Critically, these narratives highlight the excluding practice of reframing narrated [autistic] experiences as employed by expert outsiders (Becker, 1991; Charland, 2005; Williams, 1999a; 2006). It is this researcher's view that these new frameworks for autistic narratives are imperative to addressing individual and collective autistic wellbeing.

The themes of anxiety and depression, which characterise mental distress, arise in many theories of autism (see Section 3.1). However, they also arise in much of the writing by autistic people, which is arguably more relevant as the contexts are set by their voices (Murray and Lesser, 2006; Sainsbury, 2009; Simone, 2010b; Williams, 1999a; b). These experiences of distress frequently relate to demands imposed by cultural norms and their accompanying restrictions (Andrews, 2006). As such, they point to an entirely different agenda than that which locates a dysfunction within autistic people themselves (Beardon and Edmonds, 2007; Milton and Moon, 2012).

The importance of appropriately identifying mental wellbeing and mental distress is critical for anybody, but with many autistic people being inappropriately diagnosed/labelled as 'schizophrenic' or experiencing high levels of anxiety/depression, it is imperative that we are clear about terminology and expertise. Weich et al. (2011) suggest that 'mental health' refers to all mental states, whilst 'mental diseases' refers to pathological disease states and 'mental wellbeing' concerns the positive end of the spectrum. However, I would add 'mental distress' to this list of descriptors, as I consider this best describes and acknowledges the breadth of experiences of anxiety and/or depression (Hesmondhalgh, 2006; Hesmondhalgh and Breakey, 2001; Jackson, 2002; Sainsbury, 2009), which can last for diverse periods of time and reflects the emotional experiences of many autistic individuals. Furthermore, I am of

the view that a new agenda incorporating different autistic views on the benefits of having a diagnosis of autism, self-diagnosing, identifying as autistic or neurodivergent are diverse perspectives that enrich the autism debate.



Today there remains a paucity of appropriate training among practitioners to provide mental health support for autistic people (DoH, 2010b; Robertson, 2010b), but the autistic voice is clear, services need to be relevant as a failure to address this can, and does, ruin lives (Beardon and Edmonds, 2007). Jackson (2002, p181), a young man with a diagnosis of Asperger syndrome, states that whilst not wishing to disparage those with mental health difficulties, 'One of the worries about telling anyone that I have AS [Asperger syndrome] is that it may be

regarded as a mental illness'. Disclosure of mental distress experienced by autistic individuals may be challenging for fear of its misconstrual. My own experiences lead me to the view that practitioners should be more attentive, and the view expressed by Jackson (2002) shows that experiences are ripe to inform and reshape practice. I believe that wellbeing relates to the acceptance of people as individuals, as opposed to the clumping together of those with characteristics that are awkward and challenging to wider society. The notion of addressing a society with improved wellbeing then becomes increasingly plausible (NMH DU, 2010a; b).

The wellbeing storyline is closely intertwined with the issue of disclosure, in what contexts this should happen, if indeed it does, and the format it takes (Barratt, 2006, Pukki, 2006). Inevitably it interacts with self-esteem (Murray and Lesser, 2006) and the development of friendships and relationships (Moxon, 2006; Murray and Lesser, 2006), and particularly as an individual matures and becomes more independent (Graetz, 2010; Whitaker, 2006). In addition, life transitions bring various demands, and within Higher Education establishments, reasonable adjustments are frequently not attended to by staff as a lack of awareness of autism among some often means that course demands, for example in respect of group work, place considerable pressure on autistic students (Beardon and Edmonds, 2007). The resultant social overload can lead to increased anxiety, poor attendance and reduced grades.

The above highlights key aspects of wellbeing and how autism is located within this. For this reason, it is evident that the autistic voice is of paramount importance in the shaping of services.

Summary

This chapter began with a detailed overview of my meta theme: autistic people's view on their involvement informing service provision. To make sense of this, I reviewed current legislation and theories impacting on the field of autism before exploring literature around key themes, namely identity, context and power and wellbeing, raised in the evaluation of the support service for autistics underpinning this study, and from where I collected my data. These are addressed by my research questions. For services to be inclusive, the statement by an autism rights activist reflects how autistic people would like to be involved:

Collaboration with Autistic People

“...places the voices and perspectives of self-advocates at the centre of the autism conversation, as we can speak with unique legitimacy and voice about our own lives.”

Ne’eman (2011) <http://www.talkaboutautism.org.uk/page/liveevents/arineeman.cfm>

The next chapter considers my ontological and epistemological approaches to autism.

Chapter 3: Theoretical and Analytical Framework

Theoretical Framework

Ontological Position

Epistemological Position

Development of my Analytical Framework

Interpretative Phenomenological Analysis

Narrative Analysis

Critical Discourse Analysis

Reflection on the Development of my
Framework

Summary

In this chapter, I discuss the ontological and epistemological positions that informed my study. In addition, I take the reader through the rationale behind the choices which have shaped my research journey and the development of my theoretical and analytical framework. This concerns reflection on the purpose of social theory regarding the real life experiences of autistic individuals, the contextualising of experiences and identification of the location of power in order to build my framework. My exploration examines my decision to combine the diverse tools provided by interpretative phenomenological, narrative and critical realist perspectives in enabling the small stories to be heard. I argue that each has an invaluable contribution to make.

3.1 Theoretical Framework

The building of my theoretical framework was influenced and shaped by several factors, which I now discuss below.

Prior to embarking on my PhD study, personal experiences led me to question where the autistic voice was in matters impacting on and relating to autism. For this reason, I decided to explore ways to contribute to a process whereby the voices of autistic individuals could be heard - informing, guiding and shaping research on autism and consequently inclusive service provision. This process is evident across the agenda of other minority groups, including the wider field of disability rights, and is echoed in the sentiment to which ASAN (Autistic Self-Advocacy Network) subscribes: 'Nothing about us without us'. As such, I considered this to be both an exciting and necessary move towards change in a field evidencing oppression.

Reflection on the purpose and impact of social theory regarding my study seemed an interesting starting point. The critical role of real life experiences in informing and transforming service provision has been experienced first-hand by me and my family, so I sought for a way to express this in my framework. This and my wider interests in disability studies and equality and diversity led me to use the following quote by Oliver (Oliver, 1990; Oliver, 1999) as a meaningful reminder about what I wanted to explore, and the visual representation included illustrates how I envisaged the relationship of these three elements:

*'For me, all social theory must be judged on three interrelated elements: its adequacy in **describing experience**; its ability to **explain experience**; and finally, its potential to **transform experience**.'* Oliver (1990, In: Oliver 2009, p89)

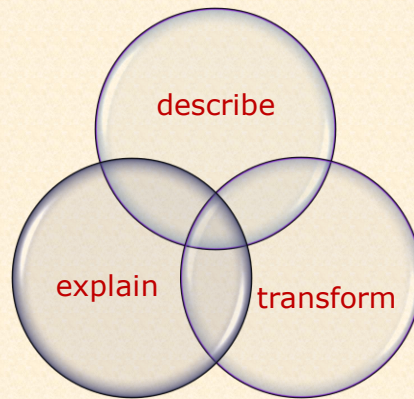
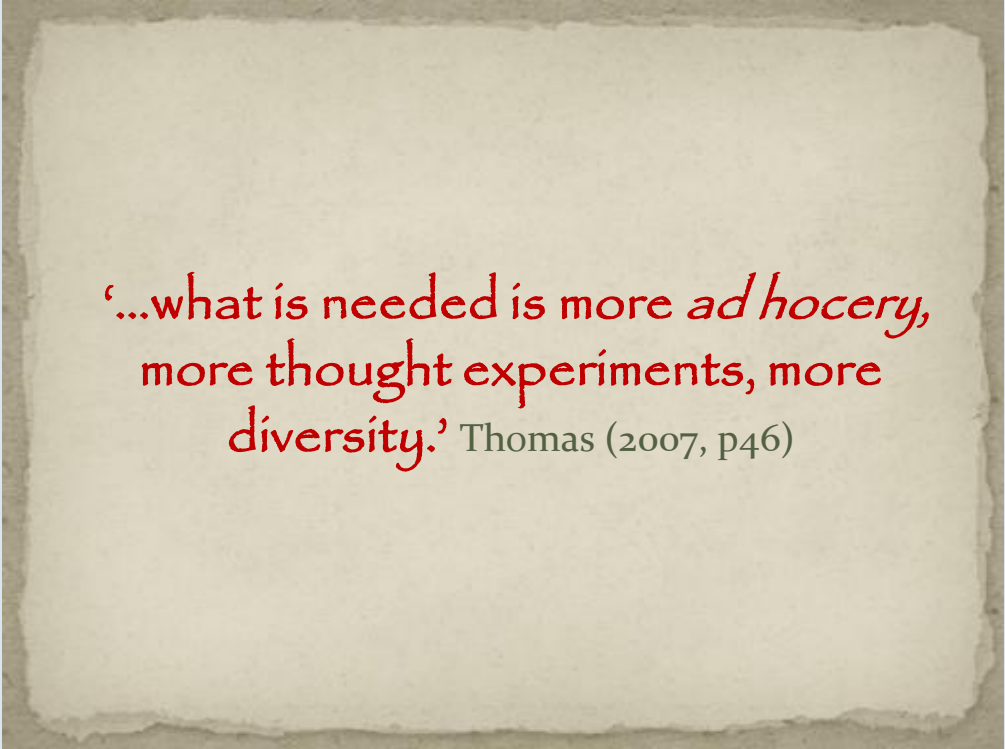


Figure 34: Illustration of Oliver's (1990) stance on social theory

In relation to the development of theory, I also reflected on the point made by Thomas, as it is one which encourages exploration and the pushing of boundaries in an attempt to make new discoveries:



*‘...what is needed is more *ad hocery*,
more thought experiments, more
diversity.’* Thomas (2007, p46)

Furthermore, Thomas also aligns himself with the view proposed by Foucault (1981, In: Thomas, 2007), namely, that theory inhibits and that creative, unpredictable and unrestricted thought are, in fact, instrumental in the development of progressive practice.

I reflected on this point time and again while developing my own framework and the elements feeding into this, namely interpretative phenomenology, narrative enquiry and critical realism. These are discussed below, together with their specific contributions to my study, and this blend is a new approach to the field of autism research.

This next section describes my positionality in terms of addressing the key points in my theoretical framework, namely describing experience,

explaining experience, and highlighting the potential to transform experience. This subsequently informed later choices in my study.

Ontological position

The first step in developing my framework concerned decision-making around the breadth and depth of experiences to be explored since my data had been gathered for the purposes of evaluating a support service for autistic people. I needed to reflect on which data to include, as this was inter-related with the experiences expressed, and subsequently provides an explanation of my choices (Ridout, 2014d; Ridout et al., 2011). Critically, it was important not to decontextualise the experiences of participants (Phoenix, 2008; Riessman, 2005).

Maintaining a focus on methods that demonstrated a respect for and acknowledged the perspectives of others was essential in tackling potential power issues which arose as a result of me being the 'new narrator' (Andrews, 2002a; Squire, 2012) of the experiences of autistic participants. This was important in recognising diverse individual and collective perspectives on autism among autistics (Arnold, 2012; Chown and Beavan, 2012; Grandin, 2009; Milton, 2012b; Murray et al., 2005). My engagement with autistic people, researchers and practitioners would, therefore, be a critical factor facilitating this. So in order for my theoretical framework to address the issue of power in relation to the autistic voice, I considered how autistic individuals engage with others in

social settings, and how the phenomenological aspects relating to all parties could be brought together without dismissing the experiences of either. Critical Realism (CR), with its tool box of Critical Discourse Analysis (CDA) is one response to this.



Figure 35: Critical Realism (author's summary)

CR lends itself well to exploring how discourse may help identify a specific social wrong (in respect of my study, the absence of the autistic voice in matters pertaining to them) and obstacles to its resolution. As such, it endeavours to 'recognise the reality of the natural order and the events and discourses of the social world' (Bryman, 2012, p29). My reading around critical discourse studies, enabled me to see how social power could be explored in terms of differential access to public discourse (van Dijk, 1993; 2008, p2). At its core, CDA concerns itself with issues

pertaining to power and control and endeavours to explore and critique societal practices and customs (Bloor and Bloor, 2007). Therefore, CDA had an invaluable contribution to make to my framework.

Fairclough and Wodak (1997) saw CDA as the social analysis of discourse, using a range of different theories and methodologies and applicable to a wide range of topics, and this was a useful explanation for me to consider. Bloor and Bloor (2007, p1) note that: 'the word discourse itself has a number of complex uses', and is often used interchangeably with 'text' depending on the situation. However, they adopt it to signify diverse symbolic human interaction, such as spoken or written text, and visual forms, such as pictures and diagrams. Any or all of these forms could mislead, persuade, or inform, and so serve to illustrate the complexities of social inequalities highlighted by van Dijk (1993). Later, in his introduction to discourse, van Dijk (2008, p1) takes this further by emphasising the development of theory embedded in this approach and combined with 'a critical analysis of the discursive reproduction of power abuse and social inequality'. The distinction is important, as power can rest in the hands of both individuals and institutions (Bloor and Bloor, 2007), and this has impacted negatively on many autistic individuals (ARGH and HUG, 2011; Beardon et al., 2009; Harker and King, 2004; Hendrickx, 2009; NAS, 2011b). These were practical viewpoints for me to reflect on in my research design (Chapter 4).

Rudman (2013) observes the need to understand how the problem and related solutions have come to be defined, since discourse occurs on different levels according to the identities at play. This relates to the argument posed by Bornstein (2013), which considers different spaces, or identities, and the regulations or rules that govern them. Regarding my study, this would concern where authority and responsibility have been situated in the construction of a dominant narrative of autism (Waltz, 2012). In addition, awareness should also be addressed concerning the power to control this definition and carry forward any action or decisions, and implicit in this is reflection as to whose needs are ultimately being met (Ne'eman, 2010). The disentangling of socially constructed problems and solutions is, therefore, a key political issue as regards service provision, and CR provides an important contribution for consideration of the identities brought by both researcher and participants.

Tew et al. (2006) argue that equality within the research context can best be obtained by acknowledging the 'unique contribution of each' and the 'pooling of expertise'. This angle offered a fresh perspective and approach to research in the field of autism, and was one that I was keen to pursue. Critically, the perspective on autism, as offered by many autistic individuals, pays attention to the issues of power, imposed identities and language that are addressed by Critical Realism (Autistic Hoya, 2015; Milton and Moon, 2012; Sequenzia, 2012; Yergeau, 2010). For this reason, the detail of my ontology introduces an autistic perspective, which

runs counter to the traditional narrative and enables the reader to determine for themselves the ways in which a non-autistic narrative has established an agenda at odds with the views of many autistic people.

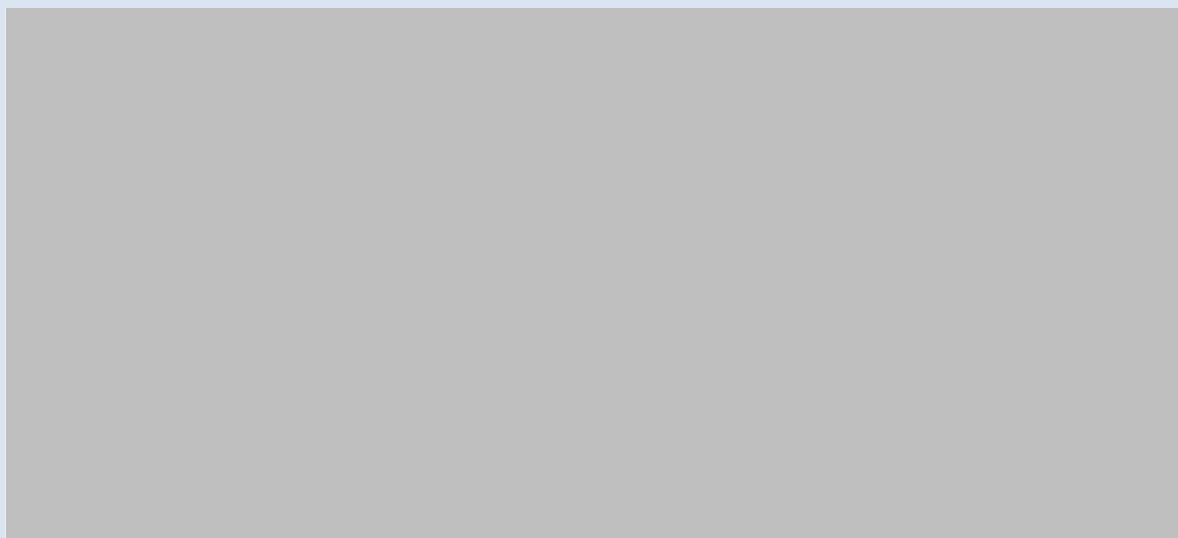


Photo: <http://www.countinggreenstars.wordpress.com>

Figure 36: Autism definition

The detail of my ontology is informed by personal experiences and those of family, friends and colleagues and reflects my belief, that social barriers and attitudes prevent autistic individuals from accessing their basic human rights (DoH, 2014c; EHRC, 1998; HMSO, 2010). In addition, knowledge of contributory factors to inclusion or exclusion has assisted me in shaping my approach. Therefore, I propose an ontology of autism, which can be explained by exploring social barriers to inclusion and a social model of disability, which includes both the structural and psycho-emotional dimensions of disability (Reeve, 2002).



Figure 37: Influences on my ontology

Initially, I considered my assumptions and made myself “familiar with the unfamiliar” (Peim, 2010) to build a wider understanding of autistic experiences, particularly the range of different and shared experiences and explanations provided. I also reflected on the diverse contributions to research and literature with autistic individuals as active researchers and writers, as this plays a critical role in redressing the balance of views on autism (Arnold, 2012; Milton, 2012b; Milton and Bracher, 2013; Murray and Aspinall, 2006; Murray et al., 2005).

As described in my literature review (Chapter 2, Section 3), autistic researchers and writers have counteracted the historical position on autism as defined by a deficit-focused medical model of disability. Rather

the autistic voice emphasizes individual differences and experiences (Graby, 2015; Milton and Ridout, 2014; Robertson, 2010b). For this reason, the diversity of autism is central to my ontology and has been informed by Arnold (2012), who views autism 'not [as] a two dimensional thing with a high and a low functioning end, but rather as a 'palette of colours that can be assembled from the primaries.'

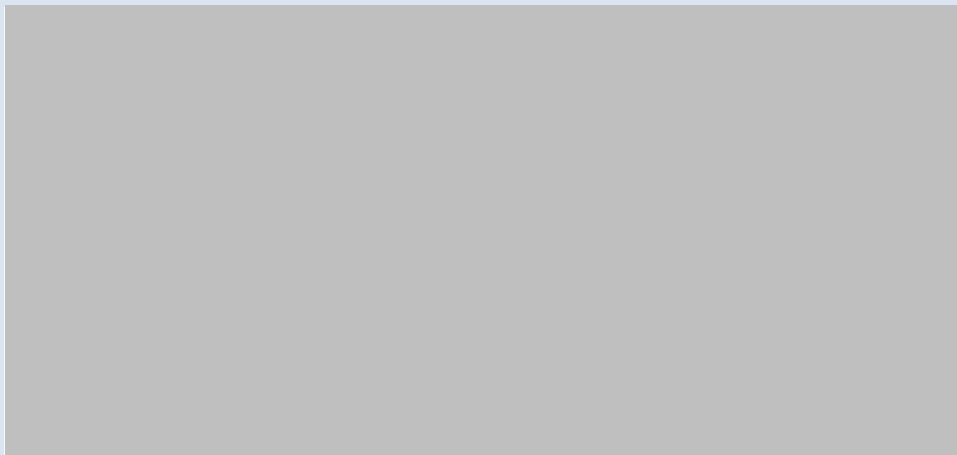


Photo: <http://www.artjustcause.org>

Figure 38: Autism and its palette of diversity

Arnold views autism as 'a landscape, where one can move within a specific territory...', and he is not the only autistic to describe autistic diversity, as Donna Williams uses the metaphor of a fruit salad to provide a visual image of the richness of autism (Williams, 2007).

My framework, therefore, highlights individuality, as it is a recurring theme in the writings and experiences of autistics. The individual experiences of family and friends added support to other narratives of insensitivity and discrimination, with an accompanying impact on self-esteem, and this is a frequently reported experience (Graby, 2012;

Greenstein, 2014; Milton and Moon, 2012; Moon, 2014b; Moxon, 2006; Murray, 2006b). Access to a support network and opportunities has had a key role in facilitating quality of life for individuals (Hesmondhalgh and Breakey, 2001; Ridout et al., 2011; Simone, 2014), and this has included friends knitted into a diversity of communities, and who have been able to enjoy their diverse identities. With a focus on independence, gaining qualifications or accessing employment, supportive communities and networks either assisted in this endeavour or at the very least maintained conversations about these possibilities (Dunn, 2014a; Hesmondhalgh and Breakey, 2001; NAS, 2011b).

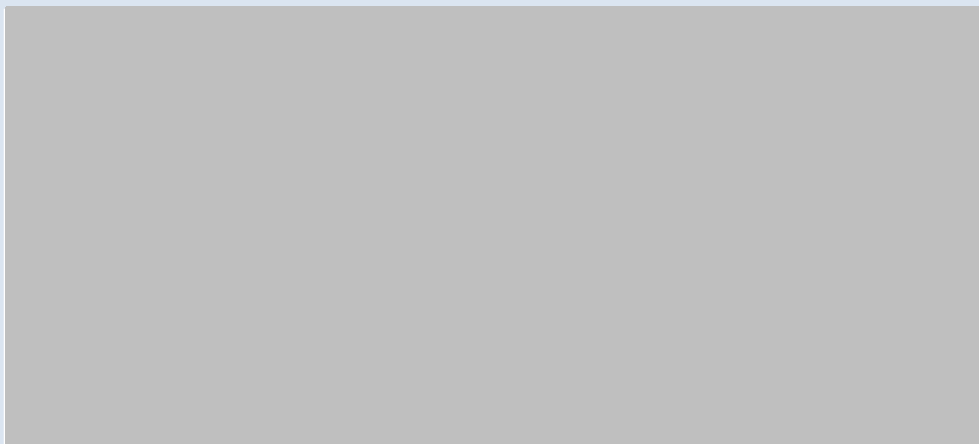


Photo: <https://countinggreenstars.files.wordpress.com/2013/11/so-gretchenleary1.jpg>

Figure 39: Sensory sensitivity

Nevertheless, another aspect informing my ontology is the impact of sensory sensitivity on autistic individuals. When combined with a lack of knowledge about autism, it has a powerful ability to skew the non-autistic person's concept of an autistic person's capabilities (Graby, 2012; Milton and Moon, 2012). For this reason, it was important to include CR in my

framework as it allowed me to explore this issue by considering the issues of power and language in diverse discourse genres (Phillips et al., 2004).

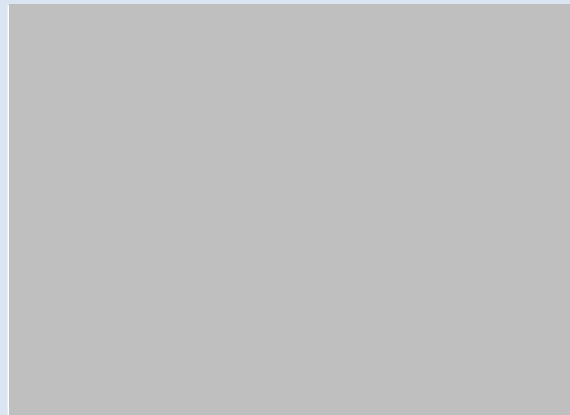


Photo: <http://www.timetochangeleeds.co.uk/when-anxiety-takes-over/>

Figure 40: Autism and anxiety

The anxiety provoked by sensory and social overload, is also acknowledged by my ontological approach, and I have witnessed and experienced the accumulating effects of these. In addition, high levels of anxiety and panic frequently result due to concern about change and unpredictability, and demands to conform to an agenda imposing social 'norms' informed by non-autistic individuals (ARGH and HUG, 2011). For this reason, I consider recognition and inclusion of the autistic voice at all levels of the research process to be integral to good practice in autism research.

Failure to include the autistic voice can only perpetuate the cycle of discrimination and exclusion, and this may then exacerbate feelings of worthlessness and negative attitudes around being different, which are often high among autistics (NAS and Ask Autism, 2014; TAP, 2014). As

Sequenzia (2012) says, acceptance is acknowledging the different communication preferences among autistics without trying to impose change.



Photo: <http://www.timeshighereducation.co.uk/news/students-mental-health-problems-highlighted/2003957.article>

Figure 41: Mental distress

Conversations with autistic friends and colleagues at Autscope 2013 and 2014 and throughout my course, in addition to personal experiences, have led me to look at the wider social impact of exclusion. The impact on wellbeing is clear: exclusion may result in isolation, which in turn often leads to mental distress. My position, therefore, is that it is unhelpful to view autism and mental distress through a medical model lens, such as that proposed by Tantum and Prestwood (1999) and Ghaziuddin et al. (2002) without addressing the wider sociological factors, such as context, power and language. CR has a positive contribution to make in listening

to the autistic voice on autism, and my view is that this is essential to balancing discussion.

Statistics highlight a lack of awareness and understanding of autism as reflected in high unemployment figures relating to autistics, with only 15% of autistics being employed (NAS, 2011a; Wallis, 2012). This is less than half the figure for disabled people employed.

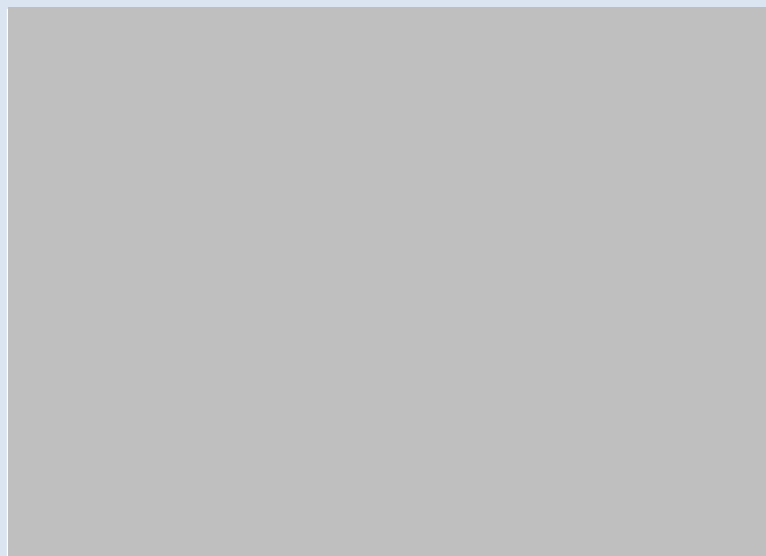


Photo: <http://www.globalnet21.org/guilt-homelessness/>

Figure 42: Unemployment and homelessness

Many autistics live a life on benefits despite being highly skilled and wishing to work (NAS, 2011b). Constantly changing government legislation (DoH, 2014a; DWP, 2013; SCIE, 2013), and regional discrepancies in support assessments and provision of services (Dunn, 2014a) make this problematic, and additional stresses may also result in homelessness (Evans, 2011; Hotham-Gough, 2013).

Social constructions of autism and what it means to be autistic may impact on the self-confidence of autistic individuals and their ability to engage in society (Lawson, 2011; Murray and Lesser, 2006). I believe the construction of and contribution to both positive and negative images is illustrated well by Lawson's description of autistic people as being differently abled individuals (Lawson, 2011, p17).

Ultimately, many autistics, whilst responding variously to a diagnosis of autism (Murray, 2006a), have expressed to me that it has been helpful in understanding contributory factors to their difficulties, such as those outlined above. Today many still fight imposed negative labels, which result in a constant need to manage feelings of anxiety, fear and exclusion.

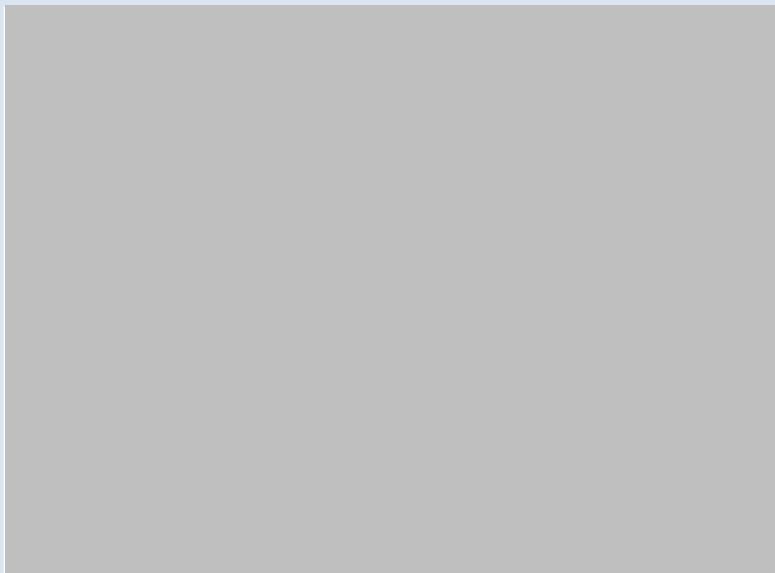
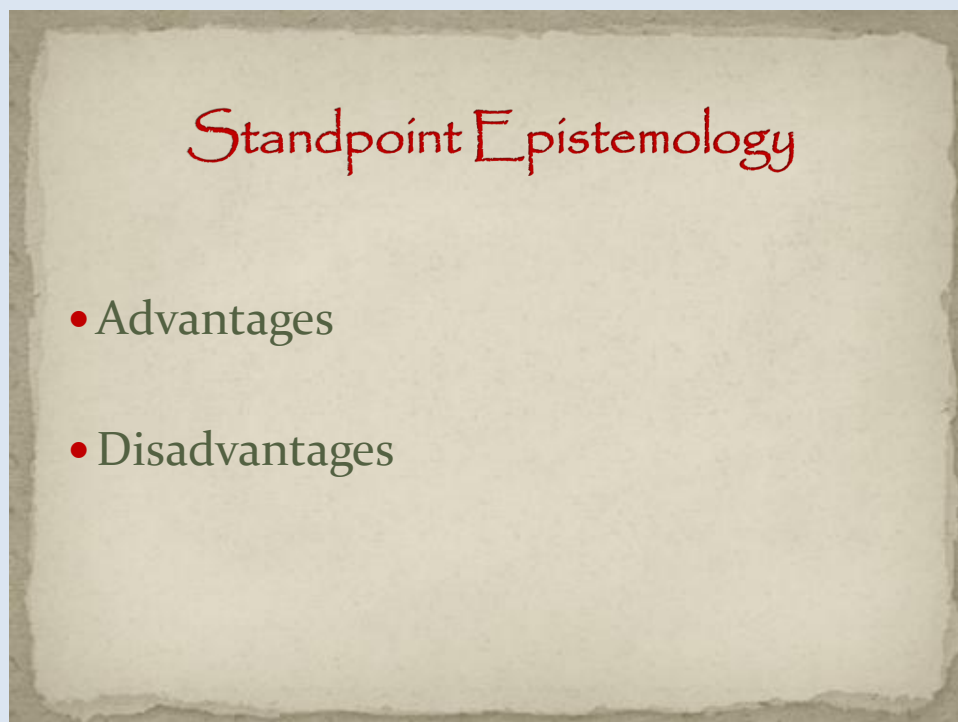


Photo: <http://www.kellymartinspeaks.co.uk/2011/06/managing-anxiety-fear-of-loss.html>

Figure 43: Managing fear

My study engages with these types of arguments and tries to explore the subjective view of autistic participants and ways in which they construct their external and internal identities. An understanding of my assumptions has crystallised during my study helping me to better articulate my experiences and those of others, and I combined the above elements to inform my choices regarding research questions, methods selected and the interpretations of participant responses.

Epistemological position



My chosen area of research has been influenced by a combination of experiences mentioned in my ontology, and my approach of standpoint epistemology (Chapter 1, Motivation). My associated knowledge of autism

and diverse societal reactions to autistic individuals and their families has, therefore, presented both advantages and disadvantages.

In discussing some advantages of this position, as someone with insider lived experience, I had prior awareness of diverse autistic individuals' support requirements concerning sensory sensitivity and overload, so was prepared to make and include adjustments in my study. Another advantage concerns familiarity with communication preferences (Allen, 2012; Brownlow et al., 2006; Davidson, 2008; Ridout, 2014d) and accounting for these in the planning and procedural stages. There was also a potential for the above to inter-relate with a dependency on family and benefits, so my awareness of this and the associated complexity of discussions and legislation was invaluable. As a 'curious outsider', I had the potential to be creative with my research to explore new and diverse ways to problematise perspectives on inclusion of the autistic voice (Arnold, 2012; Milton and Moon, 2012; Sequenzia, 2012; Yergeau, 2010), and to explore those perspectives that had been previously offered. This had the potential to place me in a position of understanding, voicing this impact more effectively.

A disadvantage of standpoint epistemology may manifest as a difficulty being objective by distancing myself from the subject of interest, therefore making assumptions that my experience was also that of a participant (Bloor and Bloor, 2007). However, as I come from a constructivist-realist perspective, I did not align myself with a notion of

objectivity, since my interaction with data sets was to be constructed in the moment (Bloor and Bloor, 2007, pp26-27). Another difficulty might be the over-thinking of my research questions by assuming that participants would address the areas that were of interest to me (Graby, 2012; Waltz, 2012; 2014). Reflecting on the experiences of those from my sample based in a specific region, and combining this with those of other autistic individuals, would potentially lead to the building of a more comprehensive picture.



Figure 44: Influences on my epistemology

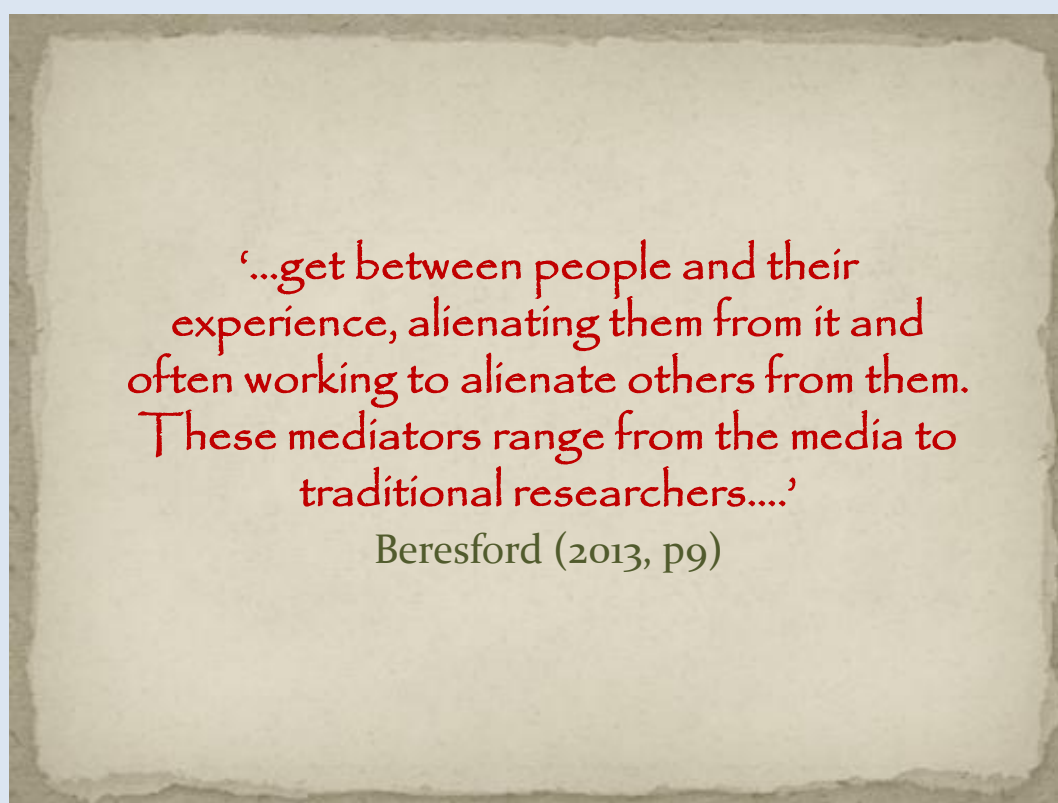
As a researcher, my role includes the conscious or subconscious filtering of information to demonstrate my view of autism. The relationship between education and political assumptions was embedded in my study, and I considered the contribution of Freire to explore this issue. I rejected

Freire's notion of the 'bank-clerk educator', who assumes students to be ignorant empty vessels for receiving and incapable of critical thinking (Freire, 1993). This would have required me to dominate participants, viewing autistic individuals as having no personal knowledge of their requirements. Rather, I turned to my natural approach, which Freire describes as the 'problem-posing educator'. As such I would reflect *with* participants, as this would provide opportunity to establish a more liberating and potentially empowering environment, where encouraging and listening to the views of others played a critical role. This style has been described as more organic as it reflects the natural talents of individuals and believes in innovative approaches (Robinson, 2010; Robinson, 2006b). The development of a design characterised by more organic elements seemed to me to be a process more welcoming of autistic differences and encourages expression of their views.

A further influence on my epistemology is my view that education should concern an understanding and teaching of human rights. This embraces issues relating to equality and diversity and recognises the need for effective implementation of equal rights in respect of access to services and support requirements (HMSO, 2010). Evidence from personal and shared experiences demonstrates societal barriers and poorly implemented government policy, which impact adversely on both the individual (in terms of life opportunities and experiences) and society

(losing resources) due to the denial of equal rights. For this reason, effective engagement with individuals and communities is critical.

Dealing with diverse identities and experiences by using appropriate, relevant and flexible methods is key to opening up opportunities for discourse, and Beresford (2013b, p9) notes how mediators frequently:



For this reason, Beresford argues that only those with lived experience are in a position to research. Whilst I can see the temptation to adopt this position, particularly in light of my own experiences, I feel that welcoming discourse with a wider community/communities, and acknowledgement of shared spaces, is perhaps more helpful as a way forward. That said, it is my view that those with lived experience [of autism] should be considered

to be the experts and views on terminology used about autistic individuals should be shaped by autistics themselves (Graby, 2012; Milton, 2011b; Ridout, 2014d).

The methods that I sought to develop, therefore, were related to my standpoint, supported by diverse autistic narrative genres (Arnold, 2010; Milton and Bracher, 2013; Murray and Lesser, 2006; Sequenzia, 2012) and research (Parsons et al., 2009). These emphasize a lack of opportunities afforded to autistics either in terms of participation in society or expressing their views. As Simone (2014) observes, by using accessible methods, we 'are not increasing a person's vocabulary, rather this individual has stopped being oppressed.' This then becomes a political as opposed to an educational issue, as many methods are inflexible and fail to access the autistic voice. Simone's observation is important to my study and links to criticism regarding the validity and reliability of flexible methods in qualitative studies (Chapter 4, Section 4.8). As I wished to tap into natural interests, abilities and curiosity, this demanded a flexible approach.

Another aspect impacting on my epistemological standpoint concerned justice and fairness in relation to payment for services. I considered it useful to adapt the argument put forward by Bou-Habib (2010) in relation to fees and higher education, which argued for the formation of public policy through the consideration of the impact on the worst-off members of society. The impact of inappropriate services for people on the autism

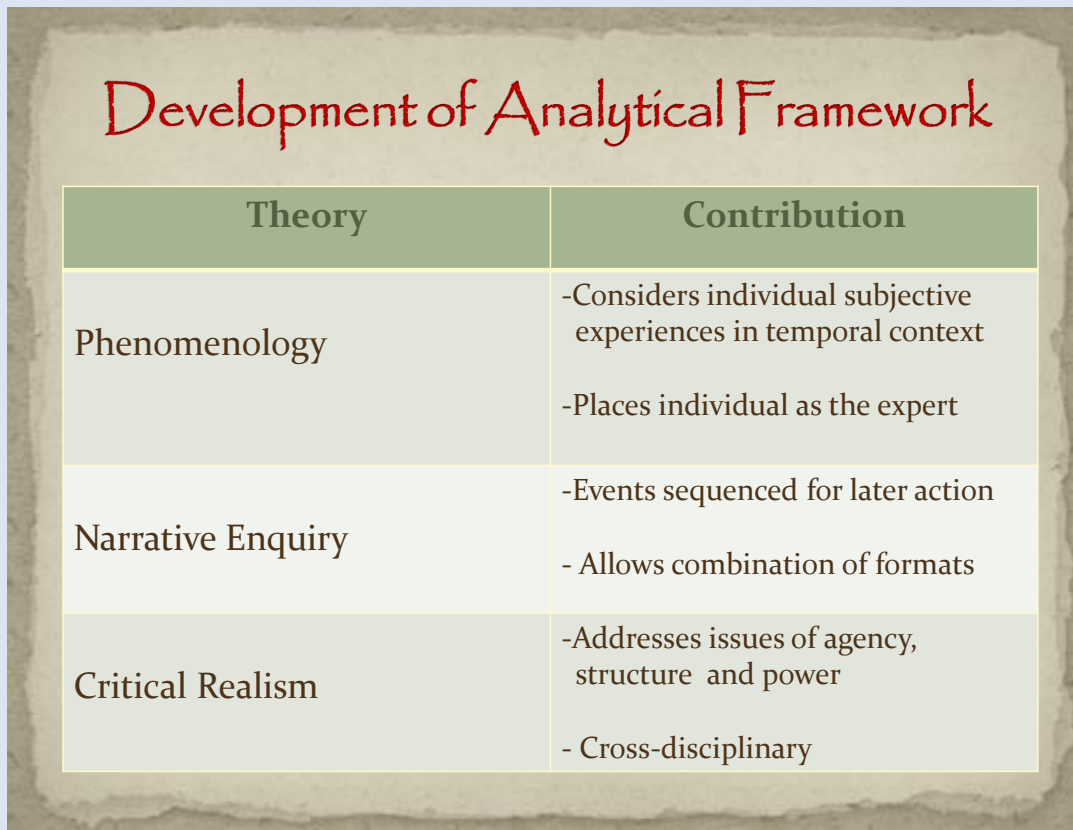
spectrum (Barnard et al., 2001) results in a high proportion of adults claiming state benefits due to unequal access to opportunities (Hendrickx, 2009; Wallis, 2012).

Research into costs of autism has taken a traditionally medical perspective (Briggs, 2014; Jarbrink and Knapp, 2001; Knapp et al., 2009), and, in my view, this has not been helped by the perspective of Autistica (2014) the main research charity in the UK referring to autism as a 'condition'. A failure to include autistic views has led to skewed and unreliable data regarding economic costs of autism on society (Pellicano et al., 2013). In addition, 'woolly terminology' used in autism-specific legislation further exacerbates the matter (ARM, 2010; DoH, 2010a). An example of this, relates to the use of the word 'diagnosis', with the implication that a 'formal' diagnosis will somehow improve an individual's life. However, the discourse around diagnosis demonstrates that many autistic people self-diagnose, and others have no diagnosis and do not self-diagnose. Furthermore, inconsistent service provision nationally often results in a formal diagnosis adding to barriers they already faced (Meyerding, 2006; Moxon, 2006; Portway and Johnson, 2005; Simone, 2010b). Nevertheless, responsibilities introduced by this legislation have informed my choice of approach, which is an abductive and arguably more inclusive paradigm, incorporating interpretative phenomenological, narrative and discourse elements.

I now discuss how my positionality has enabled me to further develop my theoretical and analytical framework.

3.2 Development of my Analytical Framework

My blend of insider lived experience and curious outsider is not atypical in standpoint epistemology (Stoetzler and Yuval-Davis, 2007). However, in my study, both perspectives were important, as I have become increasingly able to recognise some of my experiences as being similar to those of autistic individuals, whilst other experiences are entirely different. Following my initial decision to consider IPA as a means of understanding the experiences of individuals, I realised that this combination of standpoint epistemology and IPA would be a new contribution to this field and one which would also incorporate an awareness of power. Essentially, by incorporating IPA into my framework, I am challenging the double hermeneutic of curious outsider and insider, as at the same time I am offering my own neurodivergence as an alternative perspective and acknowledge neurodiversity as a key theory proffered by autistic individuals (Graby, 2015; Milton, 2014c).



Theory	Contribution
Phenomenology	<ul style="list-style-type: none"> -Considers individual subjective experiences in temporal context -Places individual as the expert
Narrative Enquiry	<ul style="list-style-type: none"> -Events sequenced for later action - Allows combination of formats
Critical Realism	<ul style="list-style-type: none"> -Addresses issues of agency, structure and power - Cross-disciplinary

Figure 45: Development of analytical framework

Development of my analytical framework required a distinctly different type of attention to that expected due to the varying nature of data sets in terms of the different contributing participants, sample size and nature of method used (Ridout et al., 2011). Whilst my study focus was on finding methods embracing the communication preferences of autistic individuals, and to facilitate expression of their voice on issues important to them, a strong sense of the telling of a narrative on autism emerged over time. Key to obtaining my data was the nature of the researcher-participant interaction, and the process of this interaction was inevitably impacted on by the experiences, identities and views of both throughout

the study (Boxall and Beresford, 2013; Boxall and Ralph, 2009; Harrison, 2002a).

Studies by researchers interested in identity have informed my own study. For example, Davies (1989, In: Czarniawska, 2004) is cited because her choice of discourse and associated tools enabled her to 'think beyond the male-female dualism as inevitable'. I was keen that a range of autistic identities emerged in my study, so that their nuances and depth could be listened to and explored, and my choice of approach was critical. Consequently, the intersectionality between oppressive institutions such as ableism, sexism, racism, homophobia and classism is acknowledged throughout (Crenshaw, 1989; Crenshaw, 1991).

Interpretative phenomenological analysis (IPA)

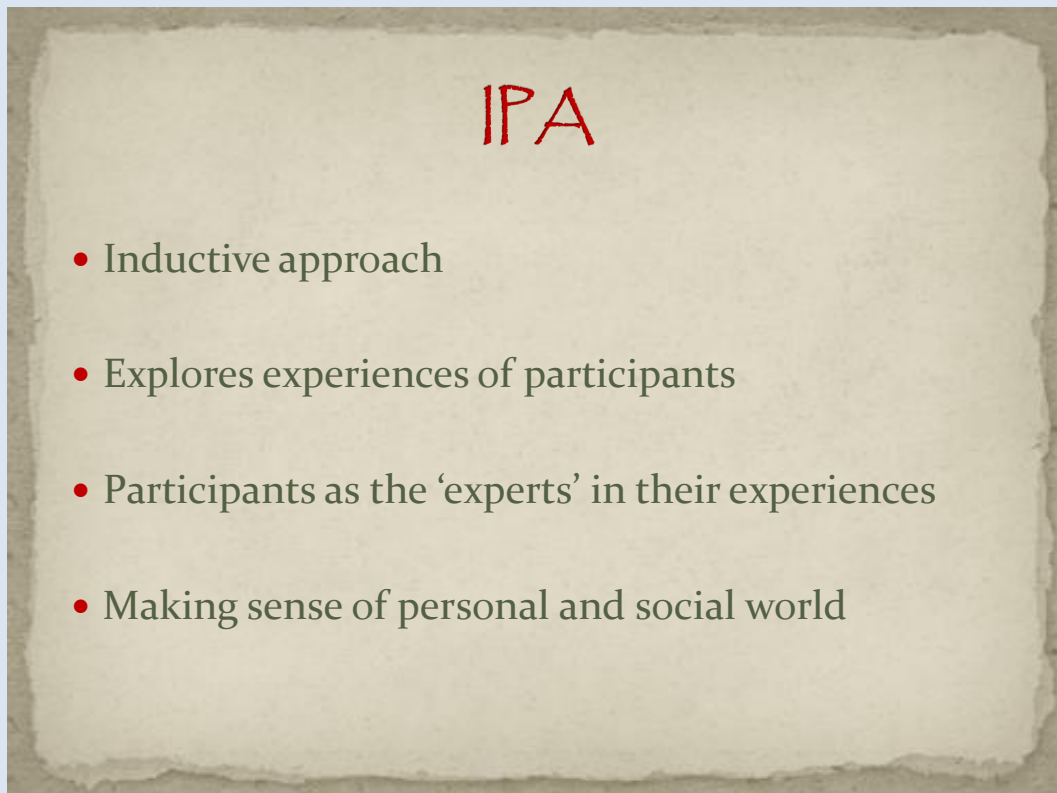


Figure 46: Interpretative Phenomenological Analysis (IPA) (author's summary)

As an inductive approach, IPA explores the experiences of research participants placing them as the experts in their experiences (Reid et al., 2005). As such, its focus is on how people make 'sense of their personal and social world', and investigation occurs into 'clusters of statements that belong together in the narratives being studied' (Smith and Osborn, 2004). IPA endeavours to understand 'an individual's perception of the event', and seeks to reveal similarities through exploration of a number of cases.

The impact of the medical model of disability as the dominant perspective of autism had led me to explore other lenses, and whilst CDA is

embedded in my ontology, I initially began by investigating IPA literature in the field of health studies, as I was particularly interested in how autistic people described and explained their experiences. Numerous studies have utilised IPA in the field of health and psychology, and a review of 52 studies highlighted two dominant themes, namely identity and the interaction between individual and societal factors (Brocki and Wearden, 2006). Of particular interest to me, aside from these themes, were the sample sizes. To assist with discovery and interpretation of nuances, numbers of case studies are typically small (Flowers et al., 2001; Howes et al., 2005; Johnson et al., 2004; Larkin and Griffiths, 2002), which is a frequent criticism of this approach (Flowers et al., 2001). However, as Larkin et al. (2006) observe, an overcautious approach by researchers is more likely to be problematic.

In response to a dearth of research on the experiences of autistic adults, Griffith et al. (2012) used semi-structured interviews and IPA as a theoretical and analytical framework to explore the experiences of seven autistic male and four autistic female adults. The approach raised useful concepts or problematic areas for reflection regarding my study. Participants chose where to be interviewed and received copies of topics to be covered in advance. Among findings noted was a possible difficulty with the open-ended nature of interviews in IPA studies. Nevertheless, autistic participants emphasized views also voiced by autistic researchers and writers (Graby, 2012; Lawson, 2001; Milton, 2011b; Milton, 2014d;

Murray et al., 2005), namely, that their position in research should reflect diversity among autistic people and be more one of expert and consultant rather than someone who is being 'fishbowed' (Moon, 2014c). This study uncovered two main themes for further exploration, relating to effort expended by autistic individuals in daily living and gaps in services such as health and employment. Also of note was the difficulty recruiting the planned participant group (over 50's) resulting in the age range shifting to 35 and above, so I needed to reflect on this issue.

Another IPA study, and in relation to identity, was by Alexander and Clare (2004) regarding the meaning of self-injury among lesbian and bisexual women. Whilst the researchers had chosen to focus their study on the 'potentially negative implications of coming out', they were surprised at how many women did think this was a positive experience and welcomed the opportunity to discuss it. The implications for my study area are interesting, as much of the research on autism focuses on negative aspects embedded in the individual, as opposed to societal causes. Refocusing the research agenda, therefore, might yield unexpected experiences of autism.

A criticism of IPA is that it serves solely as a 'descriptive methodology' of limited value (Larkin et al., 2006). However, Larkin et al. (2006) also point out that 'flexibility' as a method is in no way a substitute for rigour. Rather, they emphasise the need to ensure that 'engagement with phenomenological theory' takes the researcher to a conceptual level

beyond the concerns of participants. The study by Griffith et al. (2012) endeavoured to do this, but falls short of exploring the process of meaning making and its intersection with context and power.

There is a distinction between IPA and discourse analysis, since the former focuses on 'a clearly phenomenological emphasis on the experiential claims and concerns of the persons taking part in the study' (Larkin et al., 2006), and the interpretative element may attract the researcher's own biases. So another factor in my framework needed to address the importance of individual experiences within the context of social research, whilst recognising that individual and collective experiences are the basic tenet underpinning Human Rights legislation (ECHR, 2010; HMSO, 2010).

As a result of the lack of studies into the experiences of autistic people (Griffith et al., 2012; Parsons et al., 2009) my study required a certain respect for the contributing autistic voices not only in terms of revealing themes, but also being able to work at a much deeper procedural level. To achieve this, I decided to add to the contribution that IPA would make by considering other theories, as I felt that IPA would fall short of enabling me to link the narrative experiences of autistic individuals with those of others. One of the reasons for this was also the lack of flexibility around methods used in terms of research design (Brocki and Wearden, 2006, p91).

As my own work history centres around people's experiences and voices, for example A.C.T. (1998), this led me to explore the contributions that narrative enquiry (and narrative analysis) and critical realism (and discourse analysis) would make to this study. Addressing aspects such as wellbeing, context, power and their intersection was a critical next step, which would allow me to acknowledge the variety of situations impacting on autistic individuals. In addition, my purpose was to explore the support requirements of autistic individuals within a social model of disability context, and the discourse between parties involved was an essential element to unravel (NAS and Ask Autism, 2014). As I reflected on how the narratives and discourses of individual experiences might intertwine to form a joint narrative, I was curious as to whether I might be able to tease out the different strands mentioned as recurring themes.

A concern at this stage was how my decision-making would impact on the audience to the research narrative, and how inclusion or exclusion of the different elements would influence my reader (Andrews, 2013, p208-209). In addition, I spent some time considering whether there were any points in my study where terminology/meanings would be co-constructed using the methods chosen, or whether I would be making the assumption that my terminology/meanings would be acceptable to autistic participants (Arnold, 2013; Edwards and Weller, 2012; Milton, 2013). As co-construction marks the boundaries to some narratives, consideration of this aspect was an important issue. In IPA, participants use their own

words to describe their experiences (Brocki and Wearden, 2006, p91), but the interpretation process can result in imposed terminology, and I wished to minimise this possibility. For this reason, I then considered the possible contribution of narrative enquiry.

Narrative analysis

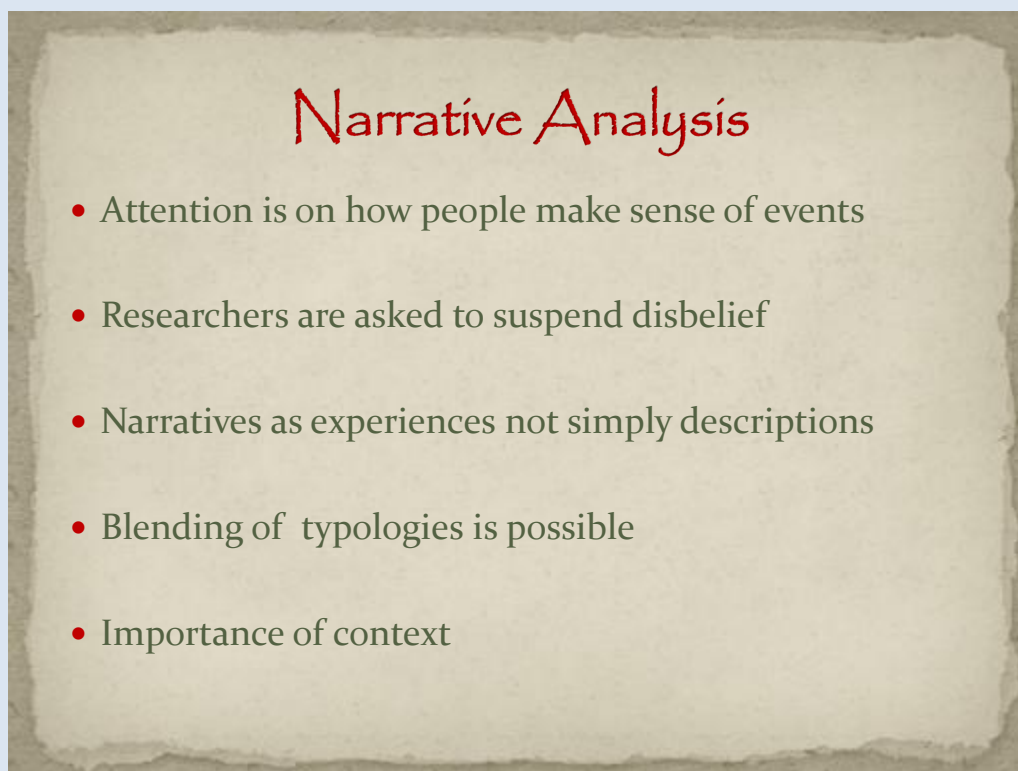
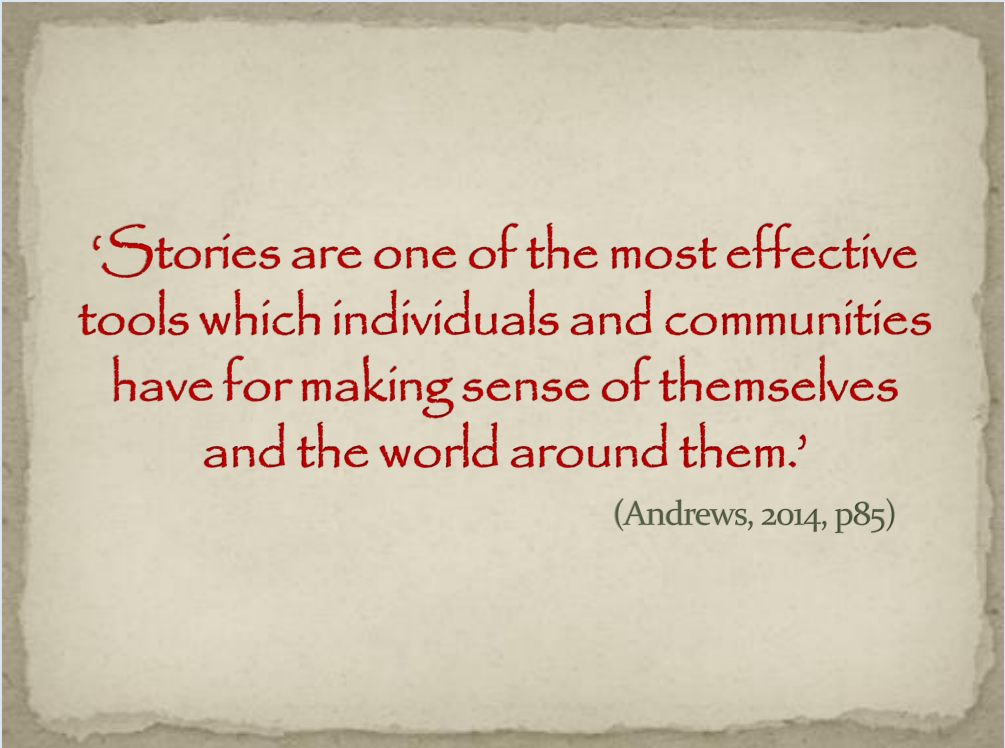


Figure 47: Narrative Analysis (author's summary)

The research challenge I set myself was to hear diverse autistic narratives and to 'assist in shifting the agenda from one of judgement to one of interest' (Luttrell, 2003, p6). I was aware that emerging narratives from individuals were still not being listened to uninterrupted, or heard, and this was highlighted by emerging literature from autistic researchers

(Milton and Bracher, 2013). This led me to consider whether a narrative theme ran throughout my study, and following discussion with a researcher in the field (Ward, 2012), I worked to investigate and clarify the differences and similarities between narratives and discourse and their possible contributions to my study.

Adopting a sensitive stance towards the temporal sequencing accessed and exploited by narrators in their storytelling (Phoenix, 2014; Riessman, 2008), narrative analysis shifts attention to how people 'make sense of what actually happened', as opposed to 'what actually happened', and it then explores how they subsequently make use of this (Bryman, 2012). Essentially, narrative analysis involves researchers suspending our disbelief and following 'the paths of the narratives which are told and performed before [us]' (Andrews, 2014 p, 32). Andrews argues that:

A rectangular piece of aged, yellowish-brown paper with irregular, torn edges. The paper is set against a light blue background. Centered on the paper is a quote in a red, serif font. Below the quote, in a smaller, green, sans-serif font, is the citation '(Andrews, 2014, p85)'.

**'Stories are one of the most effective
tools which individuals and communities
have for making sense of themselves
and the world around them.'**

(Andrews, 2014, p85)

Squire (1998, In: Phoenix, 2014) was keen for researchers to think of narratives as more than descriptions of events, but as experiences embracing small stories, which place a particular emphasis on context, a view later echoed by Bamberg (2006). Riessman (2008) discussed the different accompanying types of analysis which a researcher can select, and the nature of the information contained or eliminated from a study. Importantly, typologies, she observes, are not mutually exclusive and as the opportunity to blend them in my study was an innovative contribution to this field of work, I needed to establish which typology/typologies would assist readers to understand the message(s) presented in the thesis. Riessman (2008) proposes four typologies of narrative analysis: thematic, structural, dialogic/performative and visual, and I considered the advantages and disadvantages of each in relation to their contribution to my research questions, and my study as a whole. In addition, Chase (2008a, In: Denzin and Lincoln, 2008) mentioned five possible lenses relevant to narrative enquiry:

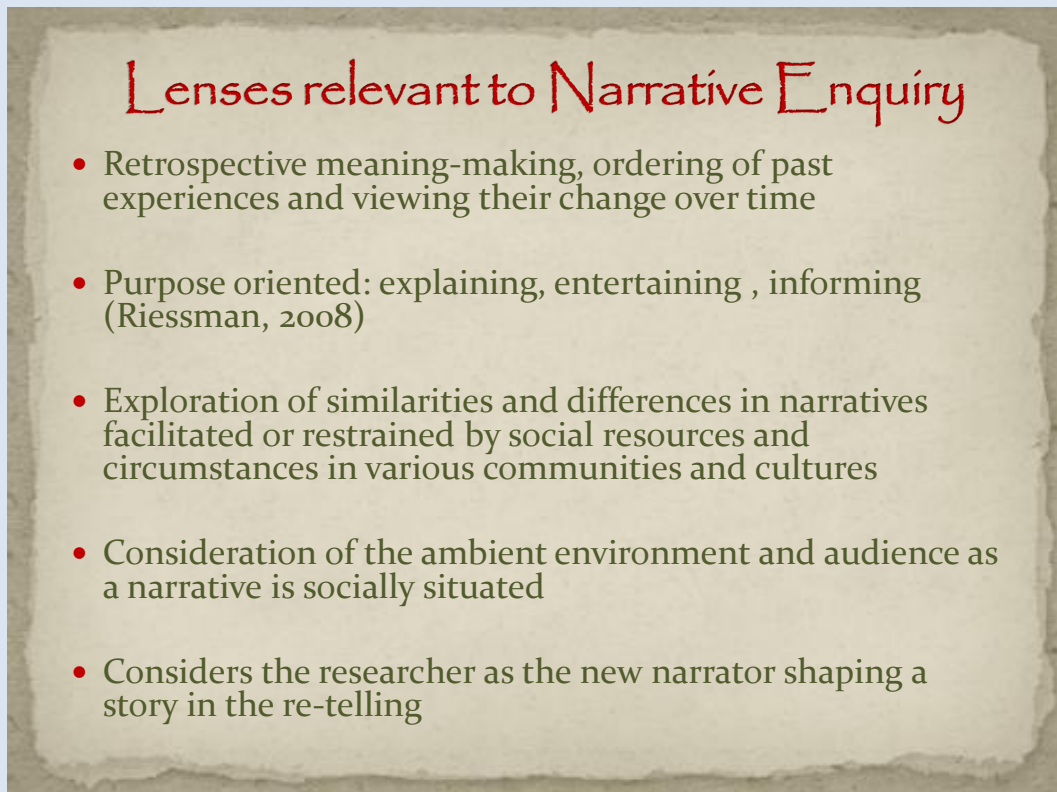


Figure 48: Lenses relevant to narrative enquiry

As a starting point, I considered the advantages of analysing a narrative as a case study, as it permits a researcher to develop categories, which may then be transferrable or generalisable to other situations, settings or groups. With the latter in particular, conceptual inferences could be made (Riessman, 2008), and in relation to this study may facilitate a process of engagement with different autistic identity groups. Nevertheless, this broad brush approach to analysis has been criticised for losing sight of the detail (Taylor, 2006), and it was detail which I wished to be at the fore of my data analysis, and to be able to 'speak for itself'. Therefore, I needed a suitable typology.

Dialogic/performative analysis would enable me to consider the contexts in which data had emerged, and the performative element linked to narration (Langellier, 2003; Riessman, 2000; Riessman, 2003). However, as I needed to be able to work across data sets, blending dialogic/performative and visual analysis proved a useful next step in constructing my framework. Furthermore, the contribution of narrative enquiry to disability studies in this way has been emphasised by Smith and Sparkes (2008), who concluded that it requires critical commentary and may well benefit from combining it with other forms of analysis.

Visual analysis has witnessed a rise in popularity, and is being used in innovative ways, such as across diverse data sets and by exploring different sites of analysis (Lutrell, 2010; Wiebe, 2013). In considering the merits of different narrative genres, Harrison (2002a) observes that the combination of photography and text is a useful method to explain the story being seen. Thus, my influence as a researcher, the setting, and the social circumstances underpinning production and interpretation of the narratives would be additional layers adding detail to this rich data. In addition, the visual methods were informed by my pilot study, personal experiences and my review of literature more broadly.

The notion of narratives as social phenomena through which social life is enacted has been stressed by others (Atkinson and Delamont, 2006), in particular, the social and cultural forces that come into play in the telling of a tale. Different uses and contributions of narrative form and analysis

in the social sciences have been described by several researchers (Czarniawska, 2004a; Riessman, 2000; Riessman, 2003; 2008; Rose, 2001), and this led me to believe that my study would benefit from adopting a wider perspective and blending a number of these. As such, I decided that narratives would be collated in different formats and placed alongside other narratives in oral, visual and written formats. Consequently, a combined analytic framework using dialogic/performative and visual analysis approaches would be used in my study to facilitate analysis of these different genres and to interpret them across data sets.

Narrative context plays a critical role in understanding what is being said and why, and although I was interested in the 'big story' being told by autistics generally, I was more interested that the small stories be heard. Facilitating this process was the essence of my study, and it involved placing narratives in context and reflecting on the narrative turn (Georgakopoulou, 2006). Through this process, it was plausible that the separation of these would distort the story being told. This also seemed to highlight the question raised by Riessman (2008 p62), as to whether we can assume that themes have similar meanings across narrators and narratives, and, by implication, context. Thematic analysis with its sole focus on content, can introduce previously formed social theory to a study to link different cases within this. This would enable me to build on the ideas of Wright Mills (1959) as my findings would then be more

generalisable (Riessman, 2005). However, as this was not the aim of my study, I rejected this type of narrative analysis.

Aside from analysing the process of the narrative and the context relating to its production, the interpretation of a narrative occurs in layers or stages (Banks, 2001). This involves the interpretation of the narrative as it is, prior to its later re-interpretation in the light of the research context. A further aspect of this thinking, is that posed by Helmers and Buhr (1994, In: Czarniawska, 2004, p37) as regards the re-telling of a story over time in order to keep it alive. The advantages and disadvantages of this are particularly interesting to me in relation to how inclusion of autistic voices in research is progressing or perceived to be progressing, and I shall return to this in my discussion (Chapter 7).

A final component that I was troubled by at this stage concerned my role as narrator, the process of the story itself or the narrative fragments selected by me from the interviews. Again, I turned to studies by others (Czarniawska, 2004a; Luttrell, 2003; Riessman, 2000; Riessman, 2003; 2008), (Luttrell, 2003) and Czarniawska (2004a) reflect on this factor in relation to my analytical approach.

In summary, narrative enquiry with a blend of dialogic/performative and visual analysis had a key contribution to make. However, there was still the outstanding question of power mentioned in my ontology, and it was

at this stage that I considered the possible contribution of Critical Realism to my research study.

Critical discourse analysis (CDA)

I believe that organisation and identification of social interactions does occur, and this view does not fit with the post-modernist rejection of order in the organisation of social interactions (Goodley, 2011, p104). However, the view held by Atkinson and Delamont (2008), was a more useful benchmark against which to analyse those interactions impacting on my study, and this enabled me to attend to the progression of the narrative of autism over time. Through the application of CDA, researchers have demonstrated the existence of diverse levels of discourse, their impact on issues of prejudice, power and dominance and that, as individuals, we act on both with and without awareness to negotiate, improve and remedy situations (Atkinson and Delamont, 2008; Cuddy, 2012). As analysis of my data required accounting for both non-verbal and verbal communication, it was critical for me to identify the textural layers of discourse involved, and this is discussed in more depth in my methodology (Chapter 4).

Maynard (1991) discusses Goffman's 'ceremonial nature of social situatedness', whereby individuals in social settings are filtered and categorised in a variety of ways, for example externally structured attributes or socially constructed rules. Both perspectives reveal varied

textures, layers and filters embedded in social interactions. As such, textures of relevances concerning interactions and the construction and recontextualisation of social rules and practice, between autistic participants in this study, the researcher and parents and staff will be explored.

Important to my framework is that Critical Discourse Analysis (CDA) places an emphasis on textual language and its surrounding contextual and social phenomena, and is a part of discourse which creates or maintains dominant groups (Benwell and Stokoe, 2012). Using the lens of policy discourse, Mulderrig (2012) explored how different aspects of language can be used by institutions as a powerful tool to legitimate decisions by misleading people into thinking there existed some sort of a consensus. Lester and Paulus (2012) observe that the 'majority of studies presume that autism organizes discourse' as opposed to seeking to explore how discourse constructs autism. However, in using a sample group comprising 'parents of children with autism and their therapists', they themselves utilise the person first language that many autistic individuals oppose (Autistic Hoya, 2015; Sinclair, 2007).

A further aspect to consider in relation to CDA, is the researcher perspective, since many are linked to attitudes and beliefs held by individuals in the discourse group being investigated (Bloor and Bloor, 2007). On reflection, I decided that the co-production process was a critical perspective to my analysis, and that I would locate myself within

the context(s) in terms of interpreting data and acting as the new narrator. My concern was that I would do the stories justice.

Reflection on the development of my framework

My framework stemmed from personal experiences and those of family, friends and colleagues in relation to autism and the wider field of neurodiversity. There were two main areas that I wished to address. Firstly, there was the issue of whether to adopt the same approach to the analysis of discourse, narratives, conversation, text and images collated. Silverman and Torode (1980) argued that it is possible to adopt the same approach to each, and saw little value in separating the two. Secondly, there was the possibility of using a different analytical approach with each narrative genre (Luttrell, 2003; Riessman, 2008; Rose, 2001; Ward, 2012). Consequently, my next step involved exploration of the contribution of diverse narrative genres to my methodology.

The building of my theoretical framework was crafted over a period of time as I reflected on how to engage with narratives produced. This was essential to reflect on prior to data collection, so that stories could be listened to with the autistic voice positioned to the fore. In addition, prior to listening to the narratives, I felt that I needed to be able to demonstrate how and where autistic voices were not being heard and how the relocation of power could assist in the transformation of experiences.

My framework focused on different aspects of each narrative, and also made use of dialogic performative and visual narrative analysis, which would not be available to readers, as an essential means of contextualising some of the experiences. Consequently, this is reflected in my discussion. The addition of IPA to my framework allowed me to place the autistic authors as the experts in their experiences and facilitate a process whereby I made sense of these, and to this, I added an awareness of power as an original contribution to the field. In addition, I was also concerned that attention was paid to the real lived experiences of autistic authors, and CDA provided me with an opportunity to reflect on the narrative layers.

The elaboration of Luttrell's (2003) methodology in relation to investigating the experiences of young Black pregnant teens helped highlight ways in which I could draw together my own data (Riessman, 2008). Luttrell described herself as working backwards and forwards across different types of data, and as with mine, these were visual, written, spoken and observational. Perhaps of further importance to me at this stage, was that Luttrell was able to maintain the focus of her study whilst engaging in this type of analysis across a range of narratives or data sets. The challenge of working across diverse data sets was becoming apparent to me, and I was aware of the need to be precise about my analytical approach and the data sets that I would access to narrate the experiences of people involved in my study. Specifically, I

needed to be considering **how (process)** the narrative/image was constructed, the **content (image)** of this, and the **audiencing**. In addition, language used and the context of the narrative/image were two further aspects to consider.

Having discussed how Critical Realism is interwoven with my ontology, and explored the possible role of IPA, narrative analysis and CDA in my study, I needed to consider how to draw diverse narratives together into some coherent whole in order to address my research questions. The potential to explore how these narratives might be usefully drawn into discourse around service improvement to address the agenda set by autistic people themselves was an aspect that I was hoping would emerge from my data. I envisaged the development of my theory visually, with each participant/group of participants having a narrative comprising numerous layers, each of which would contribute to the overall structure of the narrative. The message from each group or individual emerges as a narrative strand, which becomes entwined with other narratives in an entanglement of discourse strands. Ultimately, each fragment of the picture, each detail, would be viewed as an element of the whole narrative relating to my study title. The process relating to this is a key feature in the analysis of both the narratives and the discourse and is discussed in Chapter 5. The process is represented visually as follows:

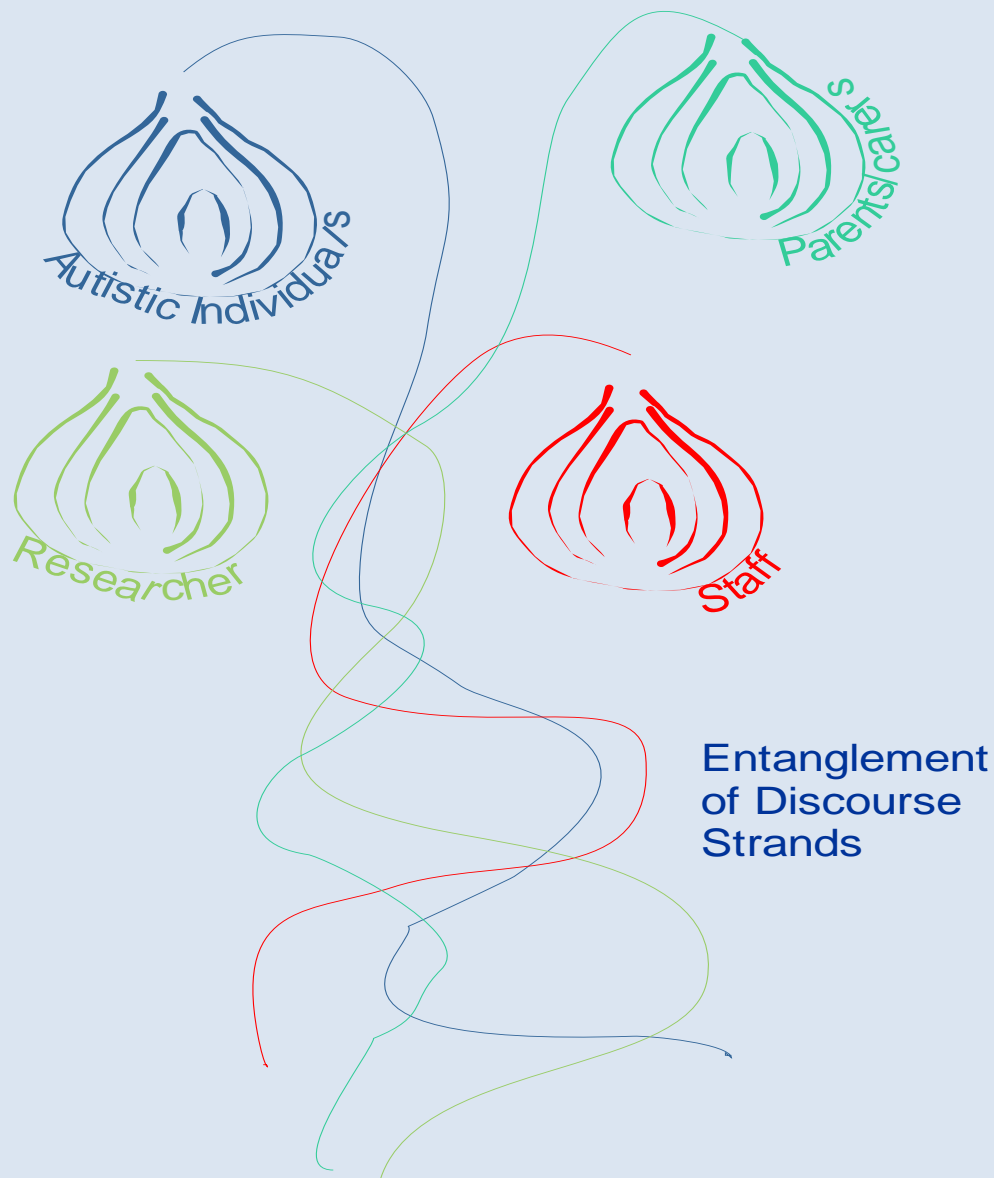


Figure 49: Linking of narratives and discourse

Summary of analytical framework

The lens through which I will look at autism for the purposes of my study has been chosen as I believe it enables me to acknowledge and explore the priorities autistic individuals place on their lives, their identities and subsequently their support requirements. I believe that the pathway towards reaching this goal lies in recognising the multiple perspectives brought by the various contributors to this study: autistic individuals,

parents and carers, social care workers and ultimately me as a researcher, and that the combination of critical realism, narrative enquiry and interpretative phenomenology facilitate this process. Following this, the blend of IPA, narrative analysis (dialogic-performative and visual) and critical discourse analysis enable me to look at issues of identity, power and meaning-making, whilst using a range of appropriate tools informed by the autistic participants themselves. Reflecting on issues of power and context in relation to sites of meaning making (process, image and audiencing), where I work across data sets is a new and, I believe, a much-needed contribution to autism research.

The above factors guided decisions informing my theoretical and analytical framework. Furthermore, I was curious as to how placing the voice of autistic individuals as the dominant narrative voice would impact on my study findings. This was a vital aspect of my study, since it would shine a new perspective on how refocusing the narrative on autism had potential to open up a different discourse agenda. My methodology, therefore, needed to be creative in this endeavour, as I wished to encourage increased participation from marginalised autistics, and show how their voice can influence and change discourse on autism.

My approach allows the voices of research participants to explain their experiences in their own words (Reid et al., 2005). Consequently, I needed to use the expressed views of participants to guide and shape the research methods in order to explore the support requirements of autistic

adults (16-25). Key to my approach was my endeavour to remain true to my belief that provision of appropriate services requires adopting a stance which welcomes debate and listens to the experiences relating to the requirements of individuals. In line with legislation, service provision requires positioning the voice of service users at its core (DoH, 2010a), and this needed to be addressed by my methodology. The next Chapter explores this aspect in more detail.

Chapter 4: Methodology

4.1 Introduction

My methodology is guided by my framework, and in particular the double hermeneutic emerging from the IPA element. Another critical element underpinning my approach is my insider-curious outsider positionality.

My research began with an invitation to evaluate a regional support service for autistic adults. Many were not eligible for care services (Fair Access to Care Services) due to being 'at the high end' of the autism spectrum, and subsequently at risk of re-entering the system at a later stage through mental health services (Ridout et al., 2011). Therefore, a short-term support service was established in 2010 by the Adult Autism and Asperger Service, and followed by the subsequent pilot of a support group (ASpire) for younger people (16-18) through the Integrated Disability Service (IDS) 16-18 Autism Pilot. The service was designed from the ground up with the active engagement of service users and carers, and feedback from those in receipt of support indicates its success (Ridout et al., 2011).

4.2 Research Questions

In order to make sense of the link between my study and this evaluation, I developed a research meta question that acknowledged that my data had been collated for the dual purpose of evaluating a support service and

listening to autistic people's experiences and voice regarding their support requirements.

Meta Question

How can data informing an evaluation of a support service be explored in greater depth in a research study to understand how some autistic individuals conceptualise their experiences?

Following this, my diverse experiences of autism led me to consider firstly, how a collection of expressive media could assist autistic people to describe and explain their feelings and thoughts, and subsequently how these narratives attended to identity and wellbeing. However, in the absence of detail about context and the location of power, narratives become arbitrary, introducing seemingly inharmonious storylines. For this reason, the purpose of my third question was to contextualise experiences and provide an opportunity for these conflicting narratives to be understood.

Research Questions

1. How do mixed expressive media enable autistic adults to voice their feelings and thoughts about themselves and their future?
2. How do the narratives of autistic adults inform us about their identity and wellbeing?
3. In what context(s) are these narratives taking place, and how is power situated within this?

These three subsequent questions arose because the autistic voice was lacking and I felt that this expert insider (autistic) voice would provide the real life detail of their experiences. My decision sat well with developments in the field emphasising that autistic people are often only asked to participate in research as opposed to influencing it at any other level (Milton, 2011b). As emphasised in my literature review, this is a concern frequently discussed within the autistic community in online forums, such as Wrong Planet, or autistic led conferences and workshops such as Autscape, Autism and Participation (Arnold, 2014b) and Theorising Autism (TAP, 2012; 2014). A more recent study into funding into autism research corroborated this and illustrated that this bias in favour of an outsider expert (non-autistic) agenda still prevails (Pellicano et al., 2013).

The purpose of these questions was to assist service providers, autistic adults and family members engage in a meaningful process to establish appropriate and relevant services. My research questions, including my meta question, have been set in my theoretical framework (Chapter 3.2) and have all attended to the describing and explaining of experiences. The potential to transform experiences may then emerge as a result of discourse that occurs during or following the construction of narratives/images, where there is room for reflection.

The theory behind my chosen methods emphasizes communication challenges experienced between autistic and non-autistic individuals as this is a recurring theme mentioned in autistic narratives. For this reason, my pilot study explored methods young autistic adults prefer to express their views, and comprised focus group activities followed by semi-structured interviews (Section 4.3 below). Following feedback from pilot participants, methods were then developed in order to fine-tune my main research design and formulate my research questions.

4.3 Pilot Study

Methods informing my pilot used by non-autistic people

Three studies used by non-autistic people which influenced my initial method design, were those by Mitchell et al. (2005) which highlighted the value of visual methodologies with young people, Social Stories (Gray,

1994; Gray and Garand, 1993) and the 'Talking Mats' technique (Cameron and Murphy, 2002). I now discuss how these lent themselves to creative adaptation to develop my design for my study purposes.

I reflected on the potential of Social Stories to acknowledge challenges, later identified as 'the double empathy problem' (Chown, 2014a; Milton, 2012a), within a process to improve understanding and communication between autistic and non-autistic individuals. My earlier involvement in a project utilising dance, drama and photomontage (ACT, 1998) had been successful in engaging young people in issue-based work, and this pointed to methods which facilitated exploration of diverse narrative genres (Mitchell et al., 2005). Personal experiences with autistic individuals have demonstrated the value of diverse methods in building a more comprehensive picture of their experiences and perspectives as told by them. This key issue of self-representation, also raised by Luttrell (2003), was relevant to my study and pays attention to participants' interpretations (self-representation), followed by that of the researcher.

Another method explored, Talking Mats, was of interest to address communication preference and ability (Cameron and Murphy, 2002). This technique involved participants in its design and emphasized the importance of being an enjoyable and engaging activity, and the visual nature of this work appealed to me.

I now discuss the methods chosen for my study, the implementation of my pilot and key findings informing my main study.

Pilot methods chosen

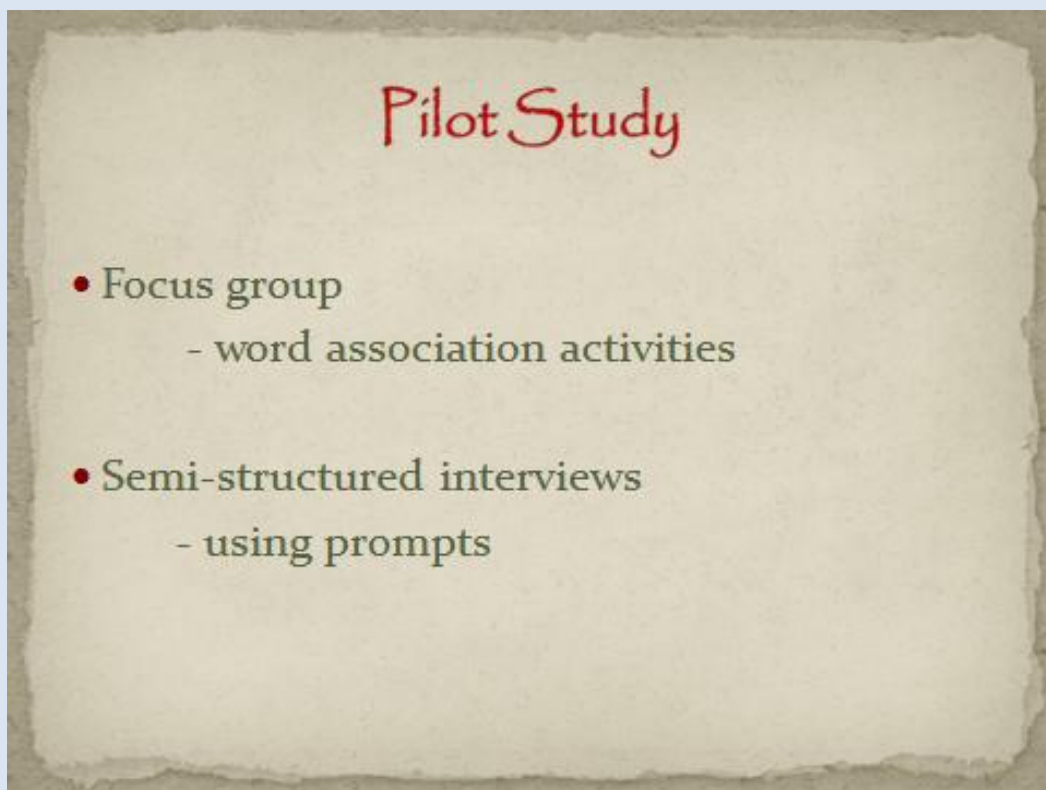


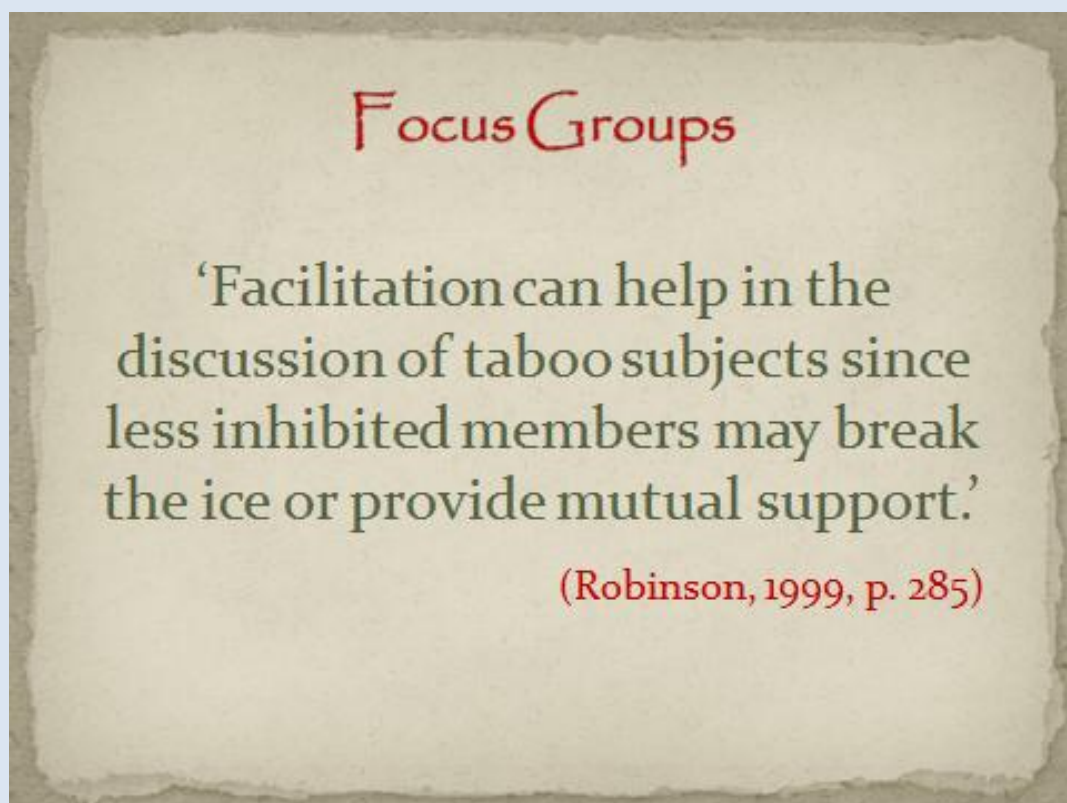
Figure 50: Pilot Methods

My pilot sample involved two individuals attending a support service for autistic adults, who had expressed interest in informing methods for my pilot study following an approach from me through their support workers. I aimed to address different communication preferences at this stage with flexible methods using a mixed methods design comprising focus groups and semi-structured interviews to triangulate the data. This approach allowed participants to be key players in informing the design for my main

study and addressed a gap in previous research (HMSO, 2009; 2014; Parsons et al., 2009) continually voiced by autistics (NAS and Ask Autism, 2014). It also facilitated a more robust and naturalistic methodology (Madriaga et al., 2006).

Focus groups

Focus group activities can lend themselves to a more enjoyable, natural, dynamic, inclusive and potentially empowering group experience, particularly when led by [autistic] participants (Hill, 2006; Owen-DeSchryver et al., 2008; Whitaker, 2004).



For this reason, I chose to pilot word association games around education and employment, which I thought would provide an interesting

opportunity for participants to voice their experiences using a combination of writing, talking and visual methods. Whilst not every autistic individual is a visual thinker (Simone, 2014), the incorporation of methods which tapped into various communication preferences would maximise opportunity for individuals to engage with my study.

The flexibility of these activities was attractive to me as a researcher looking for a more inclusive approach. However, to address the social anxiety possibly experienced by participants in my study, the context and format of my research methods also needed to be flexible (for example introducing breaks), and adaptable to individuals wishing to engage in an activity, but who had anxiety around being part of a group (Attwood, 2007). This activity could, therefore, also be done individually. As part of this activity, participants were asked to write down questions they would like to be asked to enable them to talk about their experiences in order to improve a service. Both began to talk about experiences that they had had at school, college and generally in the street, so I chose to follow their lead and encouraged them to continue writing words/phrases around their experiences. In an ensuing conversation, both stated that writing questions was very difficult as they were unsure 'how to make questions' and would find it easier to help people understand their experiences by drawing.

The disadvantages of focus groups relate to the potential risks relating to confidentiality and dominant members, so I endeavoured to be mindful of

the need for good management and recognition that the group was created for the purposes of the research (Watts and Ebbutt, 1987).

Semi-structured interviews

As a second activity, semi-structured interviews were used accompanied by visual prompt cards ('employed', 'unemployed', or 'unemployed but previously employed') to help the participants stay focused on the topic (Robson, 2002). Although generally governed by agents such as context and perceptions of power, I chose this method as there was potential for interviewees to exploit the situation creatively using time factors to both constrain and allow for elaboration (Mischler, 1999). Furthermore, I wished the interview process to be more representative of a theoretical discovery of a 'dialogic' or narrativised self (Mischler, 1999; Riessman, 2008). Having explained how I defined the term 'service provider', participants were informed that I was interested in issues they considered important in order to inform service providers about their support requirements regarding employment. By asking autistic people to prioritise issues impacting on them, this addressed a gap in research to date (Milton and Bracher, 2013).

Findings informing my main study

The voices of the two participants in my pilot provided interesting and important information concerning their personal experiences, with critical messages for my main study. Whilst findings from a small sample cannot

be generalised, recognition of issues around participation need to be acknowledged (Arnold, 2014b; Baggs, 2003; Brook, 2014; Larkin et al., 2006; Reid et al., 2005; Simone, 2014; Tew, 2006).

Firstly, there was the need to make activities relevant to participants, and to keep instructions clear to help reduce their anxiety (Simone, 2010a). To support them in this, I needed to be flexible by following their lead, particularly if they were finding an activity difficult (Owen-DeSchryver et al., 2008; Whitaker, 2004). It was also important to allow time to process the requirements of an activity to enable participation (Lawson, 2011; Murray et al., 2005), and to recognise diverse individual requirements (Barrett, 2007).

Secondly, participants stated the benefits of visual methods to facilitate self-expression, focus on a subject, share experiences and to guide discussion (Lawson, 2011). In addition, use of complimentary methods was valuable (Lewis et al., 2007; Oakley, 1999), and the triangulation of diverse methods maximised opportunity to participate (Robson, 2002). This supported the need to incorporate mixed expressive media in my main study, which embraced varied preferences of autistic individuals.

Following this feedback, I decided to pursue methods which acknowledged the narrative communication preference utilised by autistic biographers

(Grandin, 1995; Jackson, 2002; Lawson, 2001; 2006b; Sainsbury, 2009), whilst incorporating both visual/photographic and voice elements. The combination of a naturalistic approach with creative opportunities (Madriaga et al., 2006; Powell, 2002) would enable me to follow the lead of the participants (Whitaker, 2004). All of these influences were taken forward and acknowledged in the analysis of data used for my main study. I then continued with an exploration of narrative and visual methods, which I now discuss.

The influence of Luttrell's work on my study

At this stage, I discovered a specific piece of work by Luttrell (2003), which captured the essence of what I was trying to achieve in my area. Using a diversity of preferred methods selected from a few offered, collage, drawing, theatre and poetry, young pregnant teens generated an informative picture of their perception of themselves, both individually and collectively. This approach brought the 'insider' perspective to the fore allowing participants to respond to the dominant narrative, frequently devoid of respect towards heritage, culture and class, and where their privacy is stripped away (Luttrell, 2003). In contrast, individual insider narratives could be valued in a process which challenged judgemental attitudes and stigmatisation. This relates to my study as autistic individuals describe similar experiences or lack of respect and privacy using the terms 'zoo exhibit' or 'fishbowling' in insider narratives (Moon, 2014c; Sinclair, 2005).

By adopting an approach which permitted participants to select their preferred method of communication, participants were enthusiastic about the activities Luttrell offered (Luttrell, 2003, In Riessman, 2008). As I also wished to use methods which participants would find enjoyable, this information was invaluable to my subsequent choices. It allowed me to address the fact that previous studies tended to assume that failure to access or choose one method was indicative of a disinterest in the task or lack of a voice on the matter (Sequenzia, 2012). By introducing creative methods, Luttrell was able to address participants' initial silence and explore a wide array of emotions (Riessman, 2008). In addition, it enabled participants to use the terminology they wished to express their identities by also incorporating oral narratives (Riessman, 2008). In her study, Luttrell (2003, pxiv) had discovered that 'incorrect' terminology, that she used naturally, was perceived by the young girls as an imposed label at odds with their terminology used to express their own fluid identity/identities. This was a valuable point to address in my study as it is a recurring theme within autistic narratives (Yergeau, 2010).

Another element of Luttrell's study, which I decided to carry forward into my own, was the use of interpretation at different stages allowing the narrative to emerge across various data sets. This enabled participants to story their experiences by looking backwards and forwards and allowed the interpretation of diverse methods alongside each other (Luttrell, 2003). I argue that in my study this approach is more welcoming of

different challenges and communication nuances among autistic participants. This might be due to the changing of narratives over time (Bansel, 2013), diverse communication preferences (Bogdashina, 2005; Murray, 2013; Shepherd, 2008), sensory perceptual issues (Bogdashina, 2003; Grandin, 2002; Irlen, 2005; Sainsbury, 2009), or distress caused in relation to a lack of understanding of autism (Baggs, 2003; Connor, 2013).

Luttrell's work had demonstrated to me the value of diverse methods in bringing different perspectives to the table (Luttrell, 2003), and this influenced my study and pointed to the benefits of accessing and acknowledging various autistic perspectives. The advantages of using a combination of qualitative methods is that they can delve deeper into descriptions and explanations of experiences, thereby providing a deeper understanding of events than may otherwise be gained. Nevertheless, Oakley (1999) argues that context impacts greatly on the relationship between a researcher's epistemological position and decisions taken concerning the design of the research study. Consequently, I acknowledge this in discussion of my main study, as this concerned meaningful engagement with autistic individuals on methods to access their views on service provision.

Key Benefits of Combined Methods
Language and terminology chosen by autistic individuals
Communication preferences/differences embraced
Can address sensory perceptual differences
Time to Process Information and access research
Context: personal and social agenda
Diversity and inclusion addressed
Diverse contributions enabled
Power issues and assumptions challenged
Allows autistic people to select what they narrate or disclose: labelling vs identity
Enables 'coming out autistic' and avoids imposed identities

Figure 51: Key benefits of combined methods (author's summary)

Research into use of combined qualitative methods, however, has been criticised for failing to bridge the quantitative-qualitative divide. This may be due to: the prevalence of one method; the sequential, but seemingly independent running of methods, but with a preference as to which is accessed first; or with one method dominating the study (Flick, 2002, p267). For the purposes of my study, however, I do not consider this to be problematic as long as this is acknowledged and discussed.

Summary of methods of data collection

Following my pilot, findings informed methods chosen to evaluate a support service for autistic adults and a pilot support service for autistic teenagers 16-18 (Ridout et al., 2011). Data sets provided by three

autistic individuals were then selected from the evaluation as different narrative genres to explore in greater depth in order to answer my research questions. The contexts in which the data was collected are important as the backdrop to the study and are summarised below:

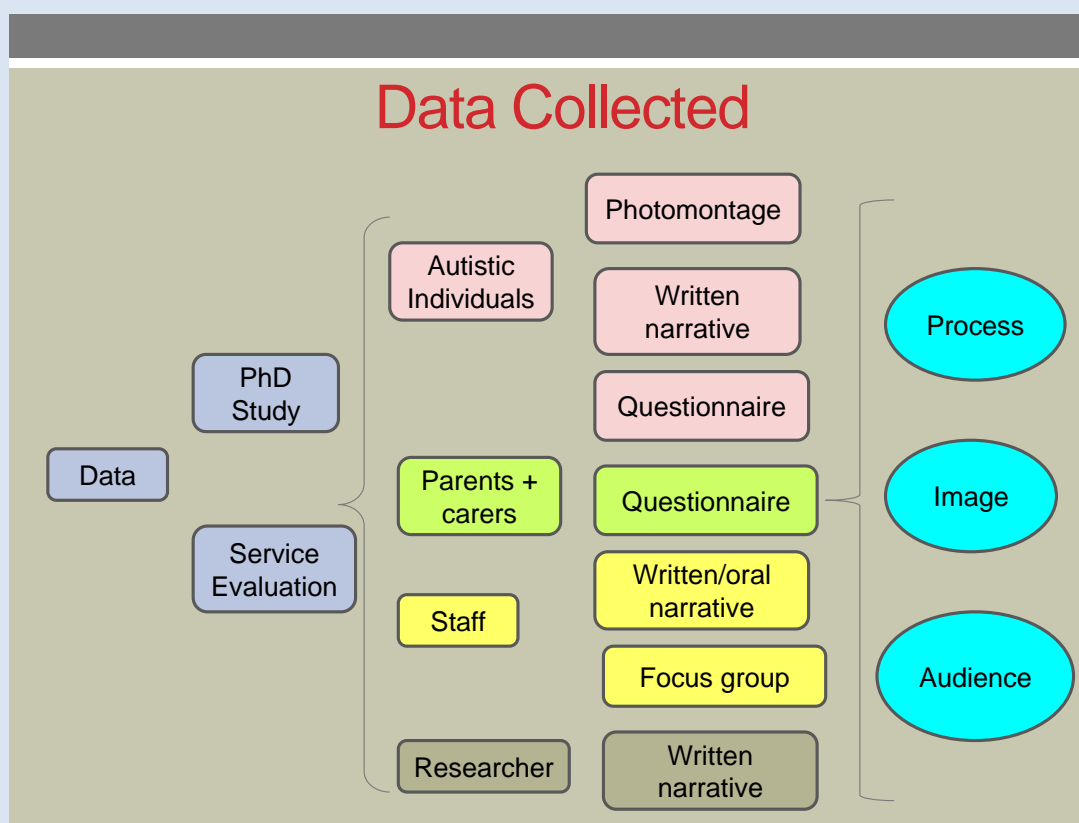


Figure 52: Data collected, which set the context for my PhD study

I now discuss my research sample and main study.

4.4 Sample and Main Study

Three cases were selected as the sample for my main study, and this was from a purposive sample recruited from the 85 autistic adults from the Adult Autism and Asperger Service and 7 young autistic people (aged 16-18 years) receiving support from the IDS (Integrated Disability Service)

16-18 Autism Pilot, which I evaluated (Ridout et al., 2011). Due to difficulties in engaging with autistic people, the recruitment rate was low, with less than the usual 30% response rate (Robson, 2002). However, this was in keeping with the IPA approach, which focuses on quality and the valuing of all experiences and contributions in an iterative process (Smith and Osborn, 2004).

The final sample of 3 was selected due to their different engagement with the evaluation of their support service. Two had completed the questionnaire and provided a narrative, and all three had engaged in some form or other with the collage process. The sample comprised two men accessing the Adult Autism and Asperger Service and one young woman accessing the IDS 16-18 Autism Pilot. Ethnicity was not recorded on the documentation provided by social care, and there was no information provided concerning mother-tongue, additional languages spoken, sexual orientation, or faith group. Two participants lived at home, and one lived independently.

In summary, the design frame for my study was based on a sample of three separate case studies, and methods informed by autistic individuals had been piloted and feedback provided.

Research paradigm

My study is primarily an interpretative piece of work, giving voice and endeavouring to understand the explanations individual autistic people

make of their contextualised experiences (Larkin et al., 2006; Smith and Osborn, 2004). As a central concern of interpretative research, the narrative of the experiences of individual autistic participants will also be contextualised. Interpretative research permits questions which explore a particular concern in a flexible and detailed manner (Smith and Osborn, 2004), and the value of investigating the views of autistic young people using an interpretative approach was demonstrated by Huws and Jones (2008). Their findings emphasised different reactions to issues of diagnosis and disclosure than that of parents. This is noteworthy as the two aspects, giving voice and contextualisation, of autistic experiences are under-developed in research (Bracher, 2013), and this is a central feature of my study.

Qualitative research acknowledges individualised ways of living and societal changes and developments, and emphasises understanding the social world 'through an examination of that world by its participants' (Bryman, 2012, p380). As such, qualitative research can be described as interpretative, and contrary to scientific research, generating theory out of the data gathered.

Case study design frame

By using IPA as a building block, my study used the double hermeneutic offered by a case study design (Brogden, 2010), which enabled me to

make sense of how my research participants made sense of their world. The study concerned a case study design around three separate individuals, and whilst each study rests on its own merits, participants were associated as a result of accessing a local authority support service for autistic adults and an associated pilot project for 16-18 year olds, this could also be argued to serve as 'a case in its own right' (Bryman, 2012, p68). In my case study analysis, I will address this point on both a micro and a macro level (Chapters 5 and 6).

An important feature of my study is the experiences of autistic individuals and the contexts in which these are storied. As a design frame, a case study enables me to explore 'context-dependent knowledge and experience', both of which lie at the heart of a case study (Flyvberg, 2004). Furthermore, using three individual case studies enabled me to recognise and formulate an understanding of differences to the norm (Thomas, 2010b). My use of case study independently increased the potential to better understand whether mixed expressive media are helpful to individuals as tools to process their feelings and thoughts about themselves and their future. This fits well with the expressed wish by autistics, to be seen as individuals (Beardon et al., 2009). In addition, the contexts in which individual narratives are taking place can be better understood, with more ready access to examine the situation of power within these.

As a strength of case study design is the provision of an opportunity to use a range of methods to collect rich contextualised evidence (Yin, 2009), I was able to use this to my advantage. I focused on the experiences and views of three autistic individuals, and in interpreting the data, the interplay between the voices of the different actors in the study (researcher/case/participant) were explored to determine the multiple realities of their experiences (Yin, 2009). My main focus concerned the generating of a description and understanding of these experiences, and the potential for using the insights that each case study generated in a wider context are discussed.

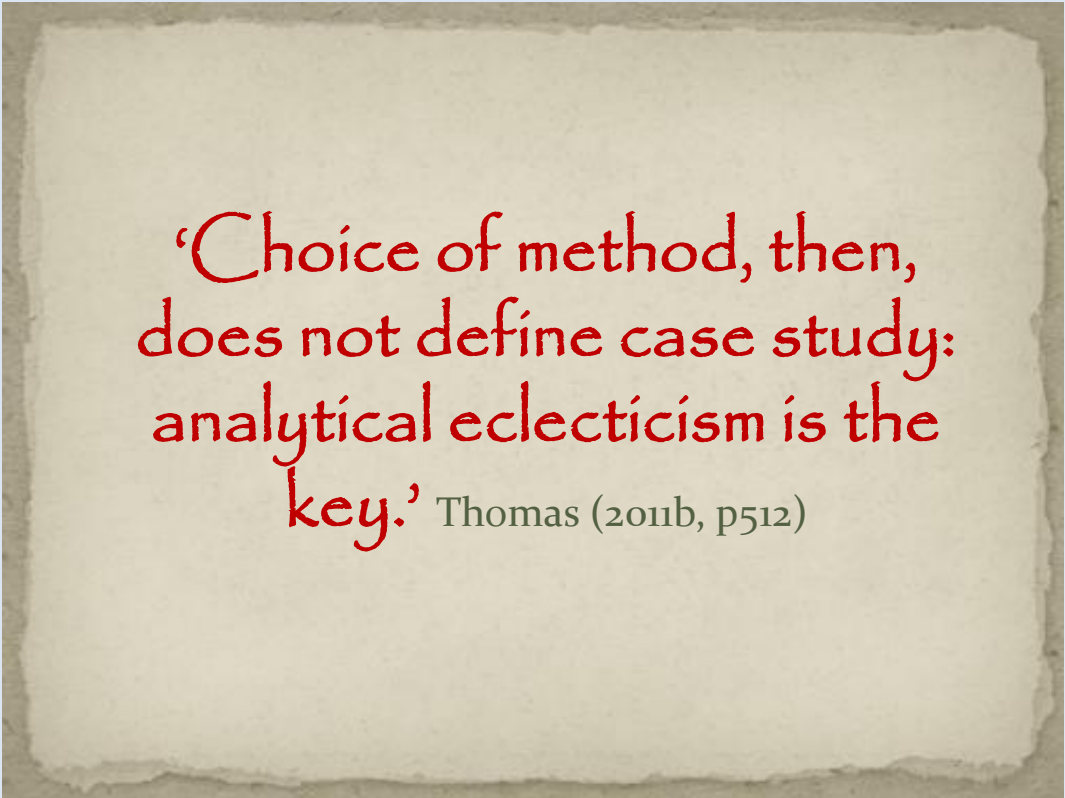
Another advantage of my individual case study approach was that the issue of power and its impact on the wellbeing and identities of individuals could also be explored in greater depth in relation to the concept of 'normalcy' (Graby, 2012). I considered individual case studies to be a useful design frame for obtaining detailed information important to individuals. Furthermore, I thought that collectively these cases might provide a bigger picture that was perhaps more representative of the shared experiences of autistics (Arnold, 2014b; Brook, 2014; Dunn, 2014b; Isaacs, 2014a; Milton, 2014a), and which would perhaps facilitate a meaningful process of communication, which would address the purpose of my research questions.

The contribution case study findings can make to the broader picture of the issue being studied has been utilised to counteract positivist discomfort with the difficulty in generalising case study findings (Flyvberg, 2004; Thomas, 2011a), which both Flyvberg and Thomas argue does not negate the descriptive phenomenological experiences of research participants. Cook and Campbell (1979, In Robson, 2002, p180) observe that the contribution of case studies to social research: 'is a fundamentally different strategy with its own designs', and this encouraged me to be innovative in my design, as did the potential of the case study design to exploring and collecting 'evidence about what is going on' (Robson, 2002, p179). Furthermore, the view expressed by Flyvberg (2004) was critical to the development of my thinking regarding the construction and destruction of single case studies. Flyvberg argues that development of a wider phronetic expertise is due to the acquisition of context-based knowledge informed by independent thinking and learning, as opposed to the attainment of generalised knowledge based on rules that underpin a case study, and this tied in with my third research question.

I wished my study to reflect the expressed wish of many autistics, namely that their experiences be understood for what they, the autistic expert, say they are (Baggs, 2003; Beardon and Worton, 2011; Meyerding, 2006; Murray, 2006a; Sainsbury, 2009; Sequenzia, 2012; Yergeau, 2010). Therefore, the narrative context, or phronesis (the 'understanding' and

'behaviour' in particular situations), addressed by my third research question, was really important to my study (Thomas, 2010b p578).

Further reflection on Thomas' argument (Thomas, 2010a) resulted in me adopting the combination of phronesis and an abductive process as a way of generating a theory around the 'best explanation for participants' experiences'. Adopting an abductive theory enabled me to attend to the minutiae of the narratives forming each case study without a reliance on 'watertight guarantees of success' regarding generalisability (Thomas, 2010a), as brought by a deductive or inductive approach (Bryman, 2012). I did this by adopting a process whereby the autistic participant was able to be the expert in their own experience, and their real world contexts in which their narratives emerged were embraced in order to recognise them as valuable events. This facilitated communication and discussion of their views around their identities, wellbeing and futures and this process enabled me to address all of my research questions. In addition, I adopted the social model of disability as the model underpinning my study and acknowledged individual and shared identities, and summarise this section with words by Thomas (2011b):

A quote is presented on a rectangular piece of aged, light-brown paper with irregular, torn edges. The paper is centered on a light blue background. The text is written in a red, serif font. The quote is: 'Choice of method, then, does not define case study: analytical eclecticism is the key.' Thomas (2011b, p512). The word 'key.' is on a new line and is slightly larger than the rest of the text.

‘Choice of method, then,
does not define case study:
analytical eclecticism is the
key.’ Thomas (2011b, p512)

4.5 Methods

This section discusses the two methods pursued following the initial evaluation questionnaire, and selected for my main study.

The shaping of my study reflected a concern that outsider expertise frequently leads to the exclusion of autistic people. Therefore, I wished to explore how use of mixed expressive media could bring the voice of autistic authors to the fore in discourse around their support requirements. As autistic participants in my pilot study had emphasised the importance of visual methods, I decided to exploit this idea by ensuring that methods were both informed by autistics and flexible in

order to accommodate communication preferences. In this way, I hoped to place the storied experiences of autistics to the fore in my study.



Figure 53: Methods use for main study

Questionnaires

The questionnaire method used to evaluate the Adult Autism and Asperger Service fed into my main study as it provided options for autistic individuals to explore their experiences further. I had used questionnaires primarily for reasons relating to time limitations, but as the information these would provide were predicted to be quite limited, alternative methods were also offered to participants to voice their opinions and potentially yield more robust data. The additional methods were narrative diaries and photomontage (Ridout et al., 2011).

Whilst the questionnaire had asked questions specific to the content and quality of the support service mentioned previously, participants wishing to use narrative diaries and photomontage were asked to story how autism impacts on their lives.

Narrative diaries

My choice of narratives to address my research questions emerged as they allowed events to be constructed by both narrator and listener and are valuable in challenging social, cultural and historical perspectives (Chase, 2008b). Essentially about 'retrospective meaning making', narrative diaries communicate the narrator's point of view, and provide a sense as to 'why the narrative is worth telling in the first place' (Chase, 2008b, pp 64-65). Consequently, narrative diaries would allow me to explore issues relating to identity and wellbeing, context and power and the creation of a meaningful process of communication between service providers, autistic individuals and family members to establish appropriate and relevant services.

Narrative diaries are flexible, allowing inclusion of text, photos, drawing, photos and poetry, and their increasing value is highlighted by autistic individuals as a communication tool of preference, and particularly to inform discussion regarding the support requirements of autistic individuals (Lawson, 2001; Williams, 1999b). In addition, Barrett (2007) found that in an attempt to address 'the fragmented approach to special

needs' (p96), narratives (an 'inside out' discursive approach) developed understanding and subsequently improved support for young autistic people. However, whilst participants may have more control over this method, they can be time-consuming or subject to a high drop-out rate, and dangers of misreporting suggest the need for a cautious approach (Robson, 2002).

Staff shortages resulted in difficulty accessing autistic participants directly, so support staff working with the participants were informed that participants could include photos, drawings, cuttings, text, poems or whatever they wished to construct this. In retrospect, in my enthusiasm to engage people in this method, I perhaps assumed that staff understood what I meant as I have a strong visual image of this. Without opportunity to run a practice session with staff, there may have been an element of confusion as to the format of the method. In addition, staff needed to encourage participants to access personal resources, such as photographs, and I did not clarify this sufficiently. Perhaps a more useful discussion would have been around what 'narrative' meant to each of us, and with some wider debate about narrative genres. Another factor impacting negatively on this method was the amount of time required for both staff and autistics to engage in the task. However, there was a good indication that whilst autistic participants wanted to join in, they needed support and specific instructions in order to do so, and this activity is ripe for future exploration.

Photomontage/collage

The flexibility of collage for opening up discursive opportunities for both researcher and participant through the reworking of images and text were apparent to me as they might enable the participant to take control and lead. For this reason, I chose collage to help facilitate the expression of participants' experiences of autism, and my approach was one of guided discovery (Kaufmann, 2006). This allowed the participant to explore their own sub-themes or those suggested by others present, namely the mothers of two participants, support workers, and a partner.

This activity was introduced by me at a support service for autistic adults, and also individually to a young teen. As a flexible stepped process drawing on ideas which can subsequently be rearranged, it was adapted by individual authors to suit their requirements. I had envisaged that participants would bring in personal photographs and images, which could be photocopied so as not to destroy originals. In the event, due to the nature of access to participants (organised through staff), administrative support, available venues and time, my communicating of what resources were needed was not as effective as it might have been. Consequently, as I could envisage that it might be problematic for some participants to organise resources to bring without support (and this would be an additional burden on already-overstretched staff) I brought in an assortment of art materials, newspapers and magazines.

Parents' narratives

In addition to the autistic narratives, a narrative text and a contribution to a draft photomontage were contributed by two mothers. Their data is included in the case study analyses to add to the narrative layers and illustrate differences in agenda and terminology. As these two points are ones which take over the shaping of the autistic narrative, they are then not included in my main discussion of the autistic narratives of experiences as offered by the autistic people themselves.

Implementation of my research design

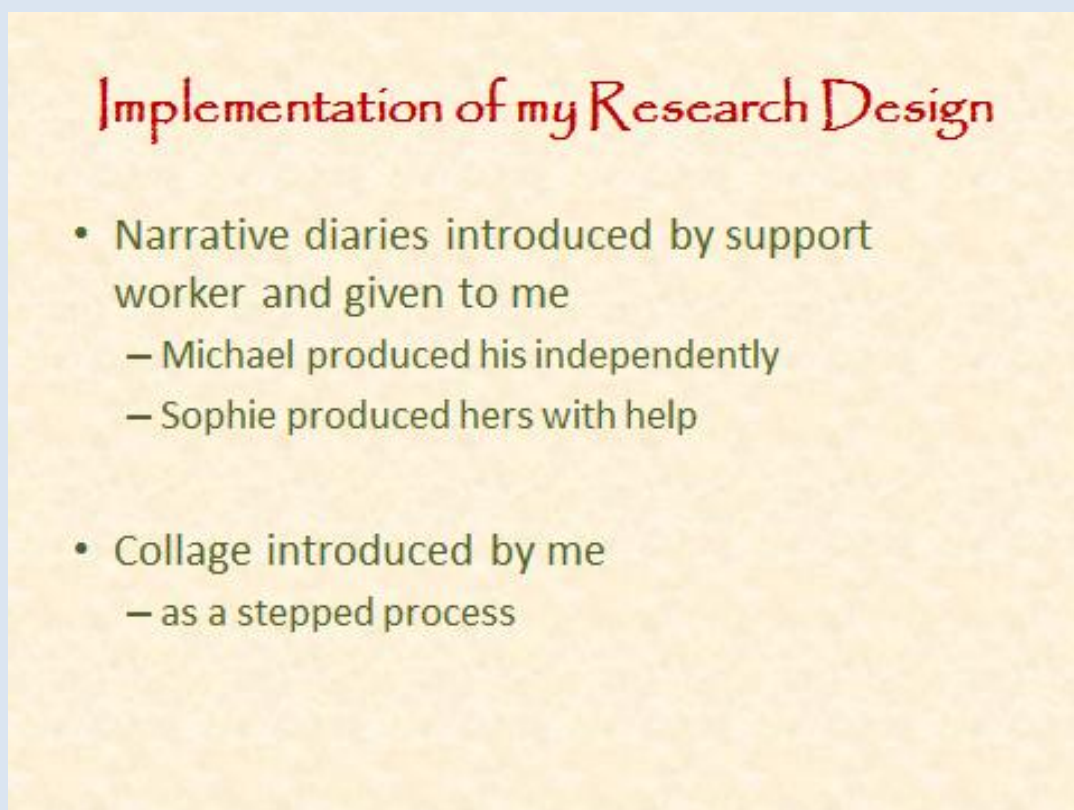


Figure 54: Implementation of my research design

Visual and textual imagery can have very different impacts, and I found myself engaging with how the images were fashioned and the subsequent

emphasis placed on words or phrases. In the collages, use of colour and different text added a sense of drama to the narratives. In addition, moving between the data sets was an exciting process as it allowed me to consider possibilities that would not necessarily arise in a single method.

Lack of information about the narrative diary contexts, such as a home or social care setting where the storying might have occurred, raised questions about possible power issues. However, the collage seemed to offset this, as the author's agency was apparent in the setting of their agenda over that of others. These methods allowed me as a researcher to push the boundaries of restrictive theory (Thomas, 2007) and to be creative. It is argued that mimesis, or gestures and non-verbal communication, is more important for communicating, and as Kupferberg (2012) observes, they give narratives a dramatic element. This was evident in the narrative produced by Peter.

Due to the diverse ways in which each individual engaged in and explored the methods, I have chosen to discuss this in more detail in Chapter 5, where I present the three different case studies.

4.6 Narratives: a justification for my choice of methods

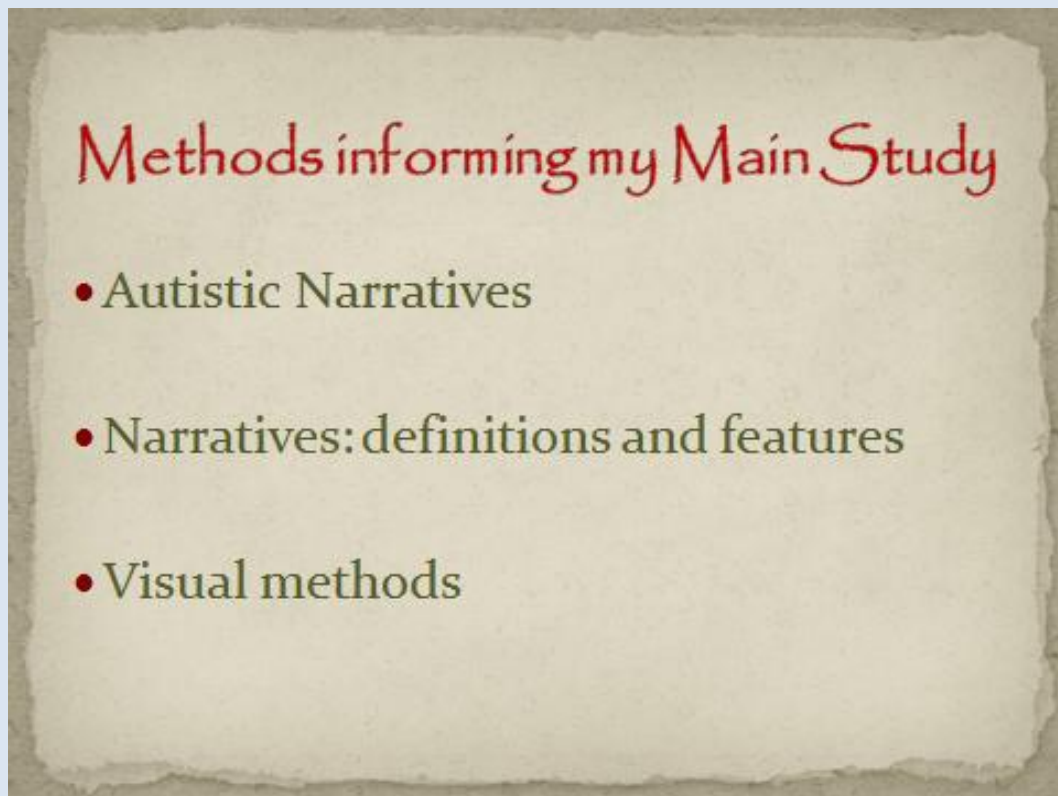
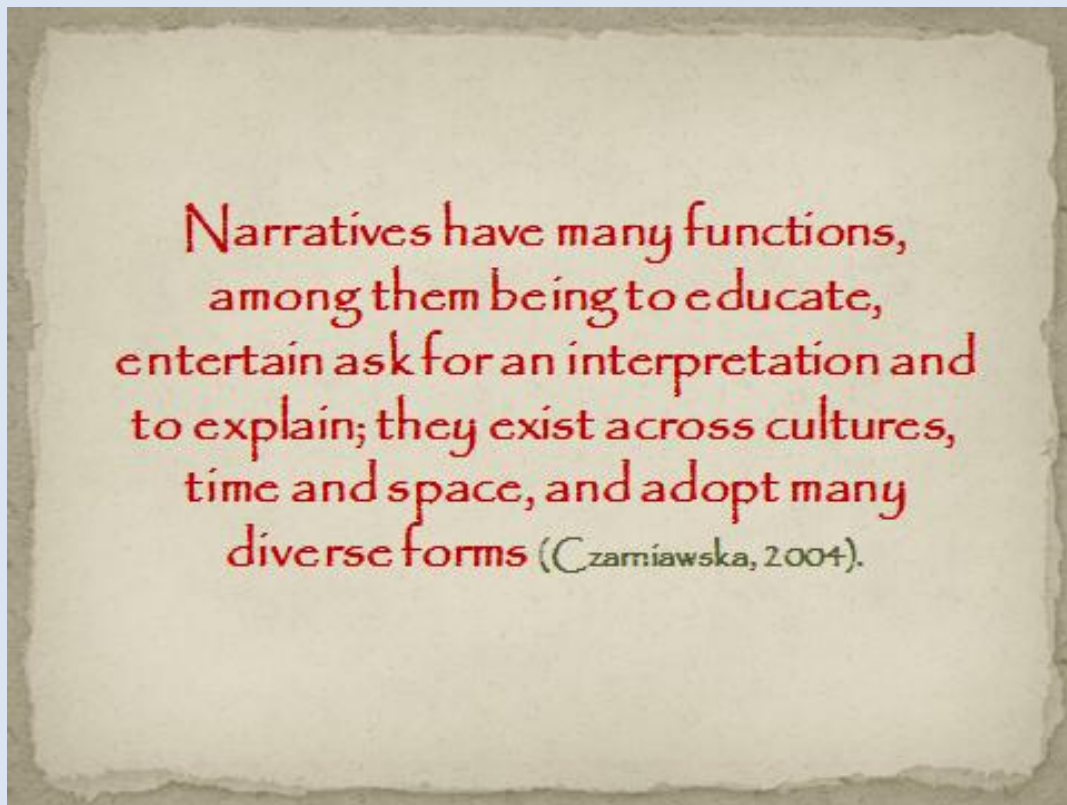


Figure 55: Methods informing my main study

Consideration of my initial data collection (Ridout et al., 2011) and pilot findings (section 4.3) highlighted that narrating experience in written and visual format was important for individuals accessing support. This next section, therefore, reviews various definitions of narrative, highlights some narrative features relating to my design and states why autistic narratives should be included in research on autism. Finally, I explore a range of visual narrative methods.

Narratives



Defining narrative is critical to my study in order to understand the nature of autistic narratives, and some definitions that have informed my research are now provided. Firstly, [autistic] narratives may be stories, chronicles or reports (Gabriel, 2000), or a form of communication (Czarniawska, 2004a, p10). They may even be *stories* of experiences as opposed to experiences themselves, since language is to do with construction (Squire, 2013, p50), and they may impact variously since it is argued that 'words can never mean the same thing twice' (Andrews, 2013). Riessman (2008, p24) considered narrative to move beyond the individual and towards the 'collective', and this acknowledged accounts of individual people's identities and an identity culture for groups and

organisations to accept or reject. For the purposes of my study, I use the terms 'story' and 'narrative' interchangeably to reflect contemporary use. In addition to this, there are key narrative components referred to throughout my study:

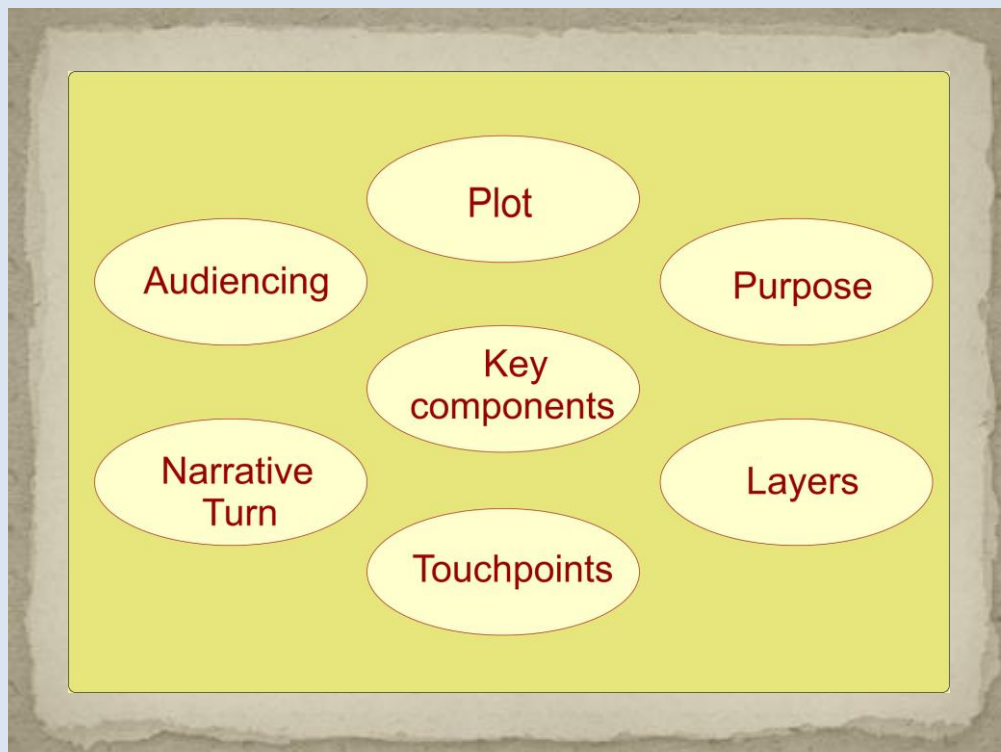


Figure 56: Key narrative components

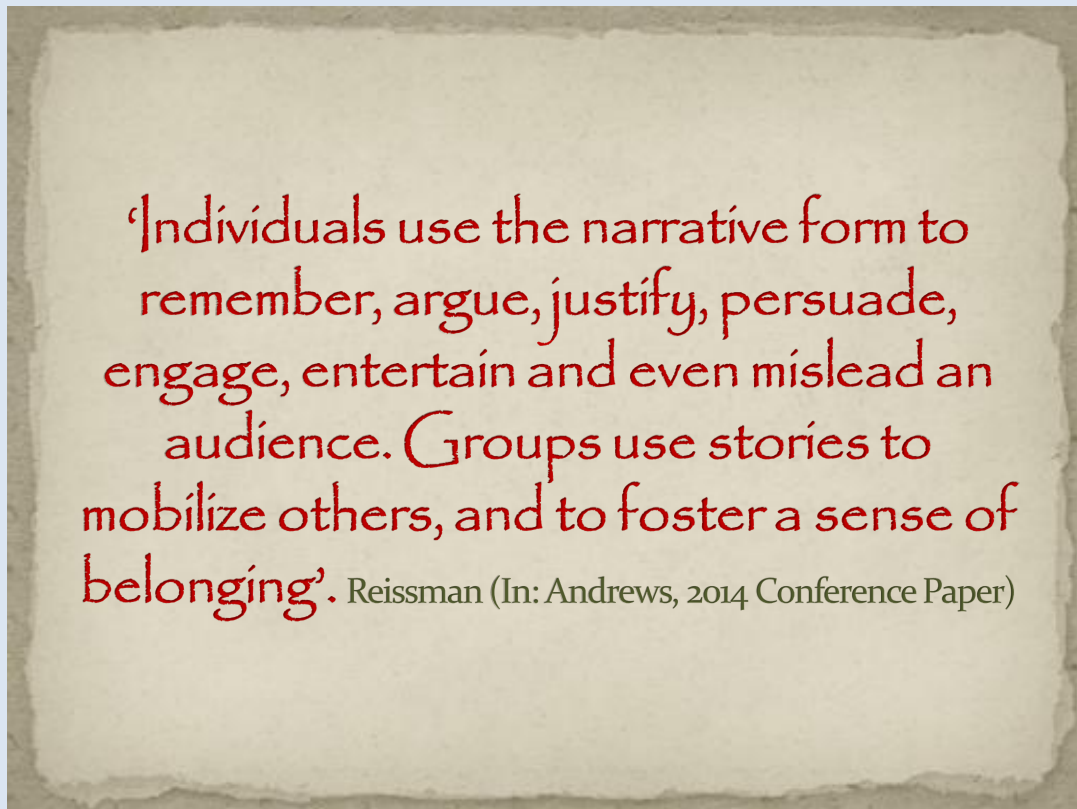
Overlaps between narration, culture and identity across numerous social spaces may provoke or awaken 'associations across time not immediately visible at the site of cultural activity' (Flores, 2000, p21). This is important to bear in mind regarding autistic narratives as they are also central to our identity, shaping experiences past, present and future (Phillips, 1993, p.16). However, the construction of autistic identities through engagement in social worlds (Bagatell, 2007), and 'the collective weaving of their places in the "webs of significance" which constitute their culture' (Geertz,

1973 In: Baines, 2012), remains weighted in favour of non-autistic individuals, who fight to maintain their 'familiar territory where they are in charge' (Sinclair, 2012). Nevertheless, stories are effective tools for making sense of the world (Andrews, 2014), and the communication of data by a researcher may also be considered a narrative (Czarniawska, 2004a, p10).

My study involves both macro and micro narratives, permitting exploration of similar and diverse points at different levels and reflection on the contingencies of storytelling (Plummer, 2014). Riessman (2008, p24) observes that the personal and temporal ordering of storied events give weight to a narrative context, and failure to share the temporal ordering of a plot can cause confusion among individuals. Besides, a consideration of the origins and consequences of a story has escaped the attention of narrative theory (Plummer, 2003), as reflected in the failure to incorporate context in autism research (Bracher, 2013).

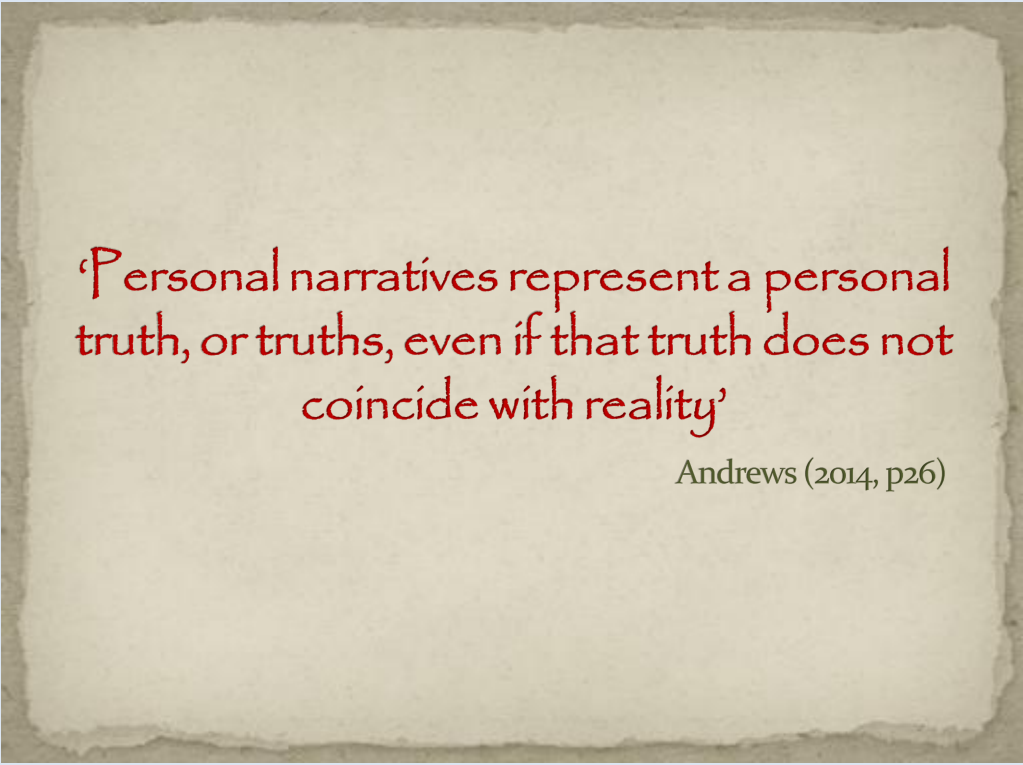
This tension is evident in the conflicting narratives of autism between autistic and non-autistic individuals, where non-autistic individuals have often made an assumption of 'shared understandings of signals and meanings' to transfer information between themselves and autistic individuals (Sinclair, 2012). Together with the problematic assumption of a communicative 'norm' raised time and again in autistic narratives (Jackson, 2002; Lawson, 2001; 2011; Milton, 2010; Sinclair, 2012;

Williams, 1999a; b), recognition of terminology autistic individuals prefer is therefore critical, and Brownlow et al. (2006) have emphasised the importance ascribed to the role of non-autistic listener in supporting the voice of autistic narrators, whilst also maintaining a marginal role within self-advocacy movements.



Phoenix (2014) argues that the acknowledgment and maintenance of small and exceptional stories is critical, and three different layers and textures of a narrative identified by Riessman (2003) are relevant to my study: the original [autistic] narrator(s), the researcher as an audience and the researcher as the new narrator of these experiences to a new audience. The researcher's perception in narrative analysis may convey

data as 'meaningful personal insights', but these may not accurately reflect the case (Czarniawska, 2004a, p50). Therefore, the involvement of narrator and listener, and their understanding of verbal and non-verbal engagement with the storytelling process, is important (Bamburg, 2012). The re-telling of specific points provides renewed emphasis, and 'positioning' permits 'locating' oneself with familiar aspects of a narrative, thereby broadening engagement opportunities for both narrator and audience (Harre and van Langenhove, 2007). There is, therefore, potential for distortion of experiences, evoking and provoking various reactions according to context, narrator and power, and this will be considered in my data analysis.

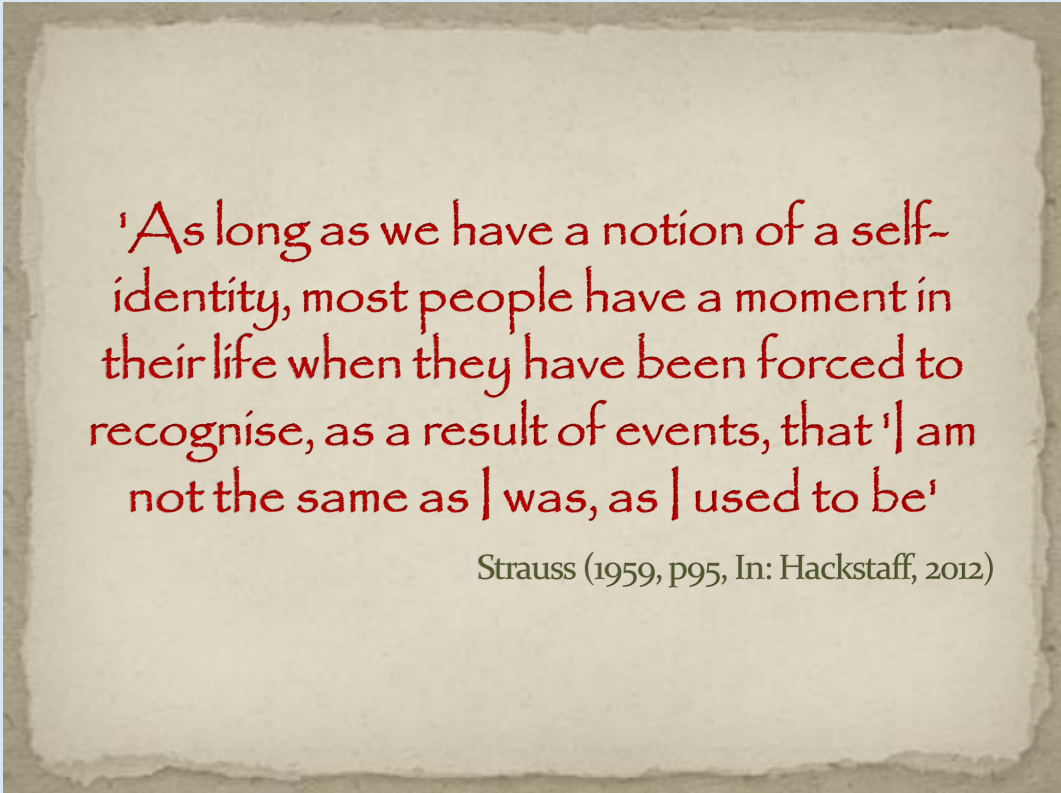
A rectangular piece of aged, yellowish-brown paper with irregular, torn edges. The paper is centered on a light blue background. On the paper, there is a quote in a red, serif font. The quote is: 'Personal narratives represent a personal truth, or truths, even if that truth does not coincide with reality'. Below the quote, in a smaller, dark green, serif font, is the attribution: Andrews (2014, p26).

'Personal narratives represent a personal truth, or truths, even if that truth does not coincide with reality'

Andrews (2014, p26)

Central to a narrative is the interweaving of emplotment and sense-making (Czarniawska, 2004a), with the former determining connections and possibly a sense of drama (Labov, 1972, In: Kupferberg, 2012). As the narrator's selection, organisation and linking of events to make the story meaningful for the audience may exist in a variety of forms (Riessman, 2008), the autistic narrative, whilst perhaps containing similar themes to others, is destined to be varied.

Operating on both an individual and community level, 'knowing' and 'communication' are key narrative features (Czarniawska, 2004a, p6), and 'knowing' is characterised by a plot, which flourishes on contrasting the known with surprise and deviations from the expected.

The image shows a rectangular piece of aged, yellowish-brown paper with irregular, torn edges. The paper is set against a light blue background. Centered on the paper is a quote written in a red, serif font. The quote reads: 'As long as we have a notion of a self-identity, most people have a moment in their life when they have been forced to recognise, as a result of events, that 'I am not the same as I was, as I used to be'.

'As long as we have a notion of a self-identity, most people have a moment in their life when they have been forced to recognise, as a result of events, that 'I am not the same as I was, as I used to be'

Strauss (1959, p95, In: Hackstaff, 2012)

This deviation from the expected is also known as a turning point, which diverges from the original life course or trajectory (Gherghel and Saint-Jacques, 2012; Negroni, 2012; Ward, 2012). There was potential for unearthing positive turning points in my analysis of the experiences of autistic participants in my research (Drapeau et al., 2007; Kupferberg, 2012), and it was valuable to recognise these as they illustrated the many successes experienced by individuals:

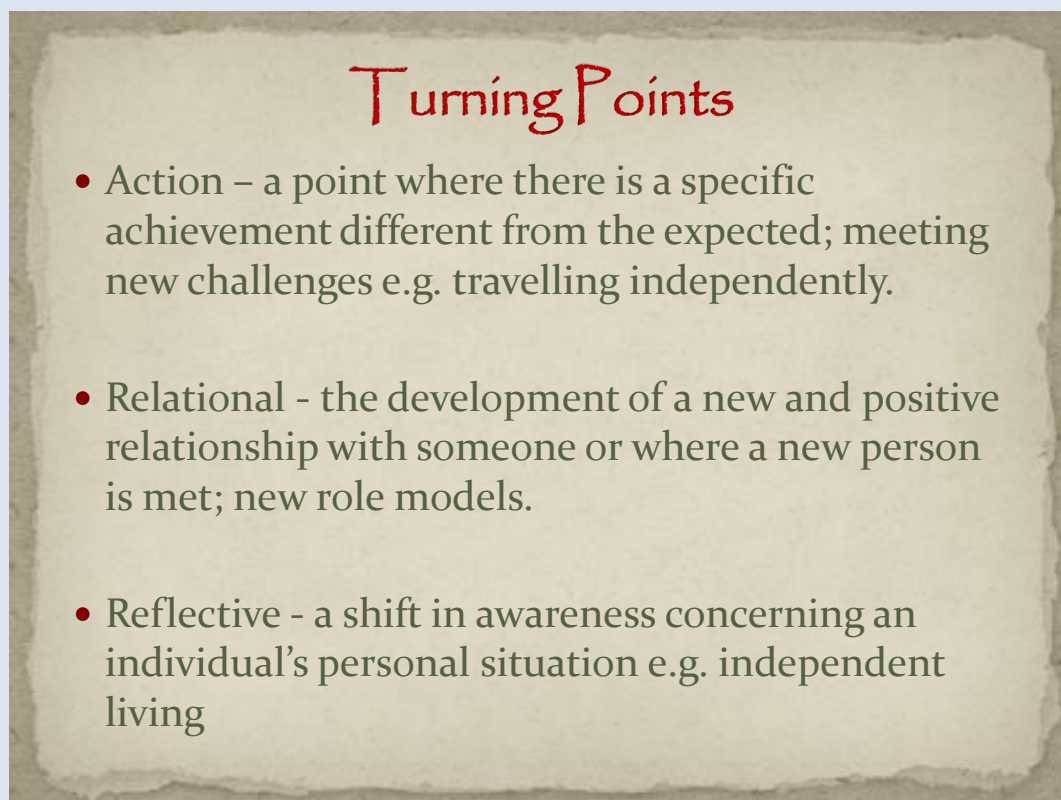
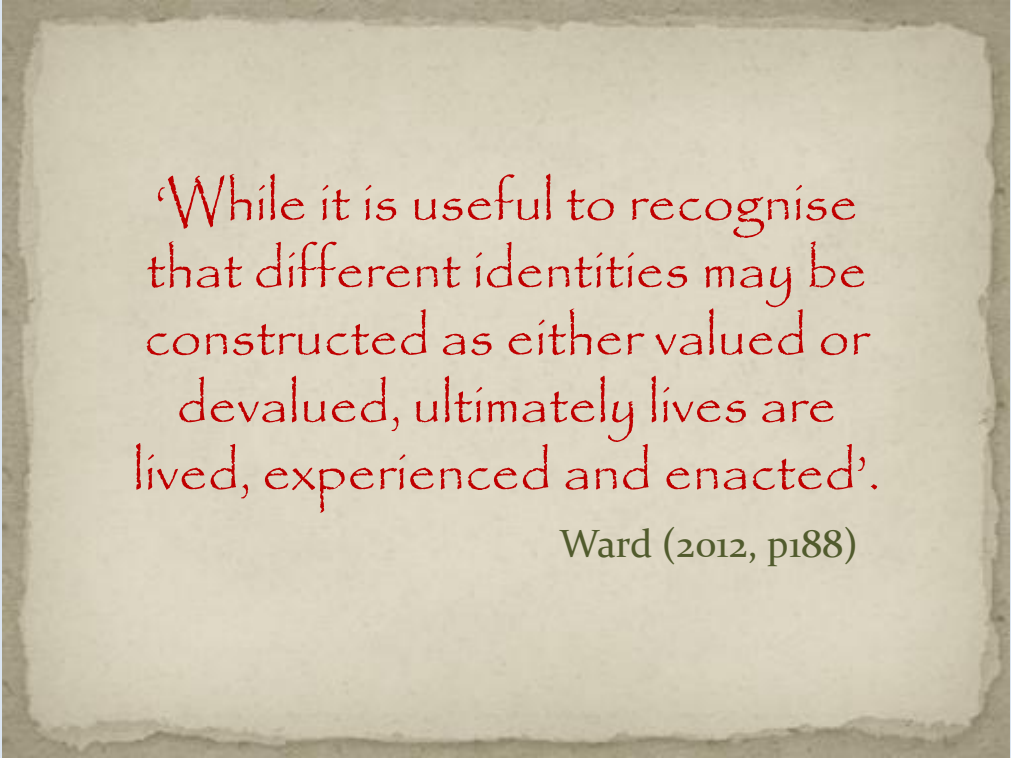


Figure 57: Turning points

Counter-narratives of negotiation and resistance in institutional narratives require coping strategies as they have considerable power to render the autistic individual at an advantage and powerful, or at a disadvantage and powerless (Lockwood, 2014), and this issue of context and power allows

me to address my second and third research questions. Furthermore, Lockwood argues that these narratives hold assumptions around the lives of individuals, which lead to the continuation of a negative subplot, and the writing of alternative stories is essential in counteracting skewed institutional stories (Plummer, 2014). In listening to the autistic voice, my study aimed to challenge the pervading sub-plot of autism, which has provided a negative framework of the individual's life as 'having been ruined'. In so doing, I respond to my research questions, welcoming and encouraging the real experiences of autistic individuals as told by them. Consequently, at this stage in my research, I chose to use various narrative genres flexible to individual communication preferences, and which would introduce an element of agency and autonomy to the methods to facilitate the narration of their identities. This would incorporate new contexts, differences and stories.

My design seemed to be following a trajectory that Ward (2012) describes as a *biographic narrative*, which is a narrative at both the stage of data collection (interviews) and analysis. There was opportunity to explore the social construction of realities, and to investigate 'the lived realities of socially constructed identities' (Ward, 2009). In this form, my study had an interesting contribution to make to perspectives on autism and identity.

A quote is presented on a rectangular piece of aged, yellowish-brown paper with irregular, torn edges. The paper is centered on a light blue background. The text is written in a red, serif font and is arranged in five lines.

‘While it is useful to recognise
that different identities may be
constructed as either valued or
devalued, ultimately lives are
lived, experienced and enacted’.

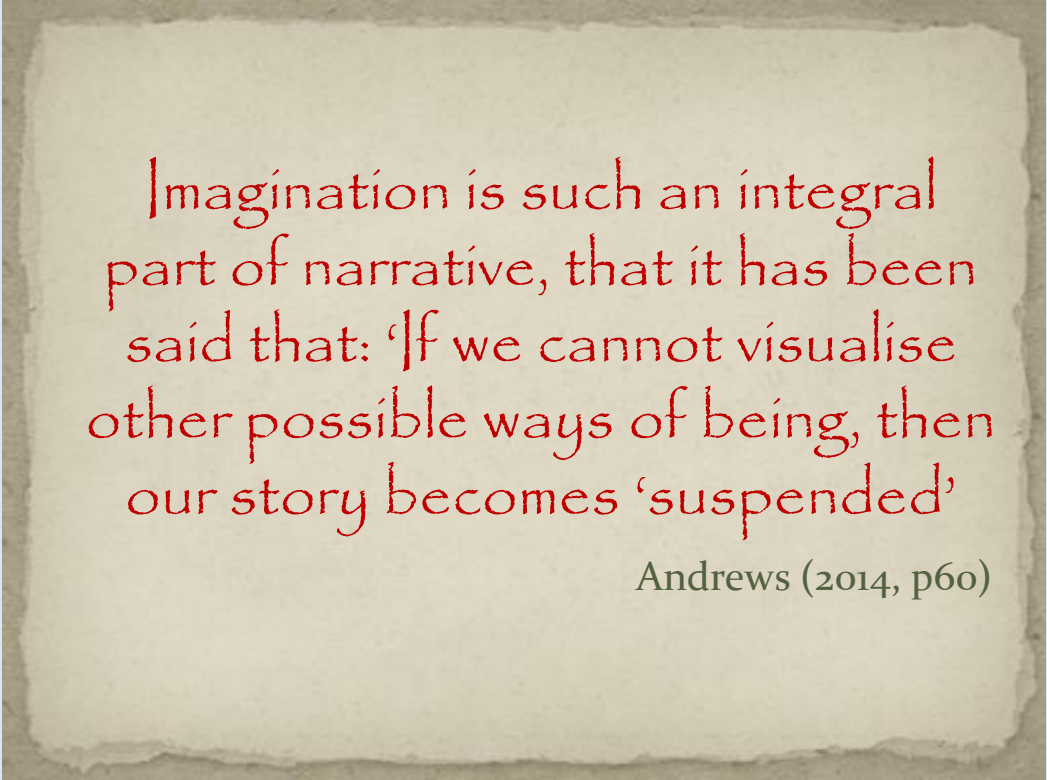
Ward (2012, p188)

The narrative turn in social sciences has resulted in an initial consideration of narrative as an enacted narrative as a basic form of life, to a mode of knowing and communication (Czarniawska, 2004a), and de Fina and Georgakopoulou (2012) have emphasized the importance of context in relation to performative and discourse analysis.

Thematic assumptions exist between narrator-listener or writer-reader, and the sequencing of events or any recurring themes or patterns in the telling is influenced by diverse social factors (Riessman, 2008). This structure may concern narrative genres; a storyline that passes throughout the entire story, and which could be retold in diverse formats

by the researcher; or a brief episodic storyline, such as poetry, used in the initial study by Luttrell (2003) which influenced my study.

Audiencing, or the capacity to engage an audience emotionally, may be considered as imperative to a story's success (Riessman, 2008; Rose, 2007), and this may also be true of the analyst's narrative ability as their interpreting becomes the next narrative. Since storytelling exists in a stream of power, shifting outcomes and distributing control (Plummer, 2014), dominant narratives essentialise and generalise the experiences of individuals, silencing other stories (Smith, 2014). Therefore, my challenge was to design methods which allowed the individual autistic narratives to speak for themselves in a manner that was both attractive and engaging, and to enable me to explore my research questions. My presentation of the narrative, therefore, needed to tap into imaginations of both autistic participants and me as the researcher:

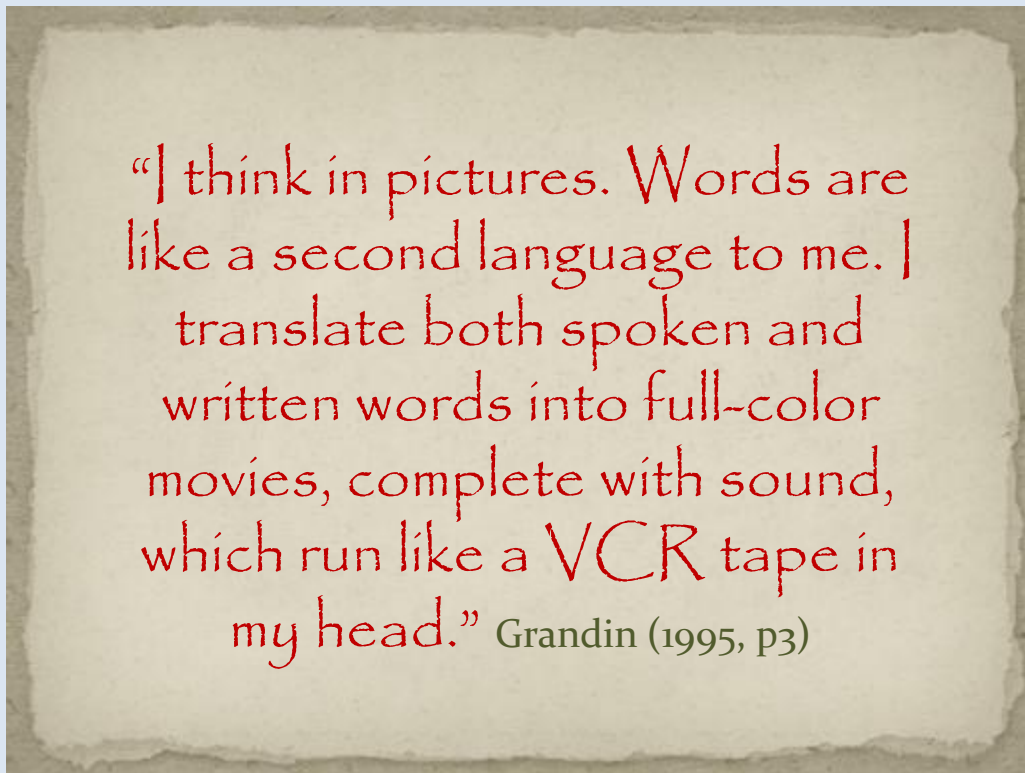
A quote is presented on a rectangular piece of aged, light brown paper with irregular, torn edges. The paper is centered on a light blue background. The text is written in a red, cursive-style font. The quote reads: "Imagination is such an integral part of narrative, that it has been said that: 'If we cannot visualise other possible ways of being, then our story becomes 'suspended'" data-bbox="217 150 800 325"/>

Imagination is such an integral
part of narrative, that it has been
said that: 'If we cannot visualise
other possible ways of being, then
our story becomes 'suspended'

Andrews (2014, p60)

In listening to perspectives held by [autistic] individuals (Phoenix, 2014) as they negotiate and renegotiate meanings of place, time and space as participants in my study, I wished to determine whether the autistic narratives which my study explored were typical of narratives across all settings, in a constant state of construction, retelling, contradiction and confirmation both individually and collectively (Czarniawska, 2004b).

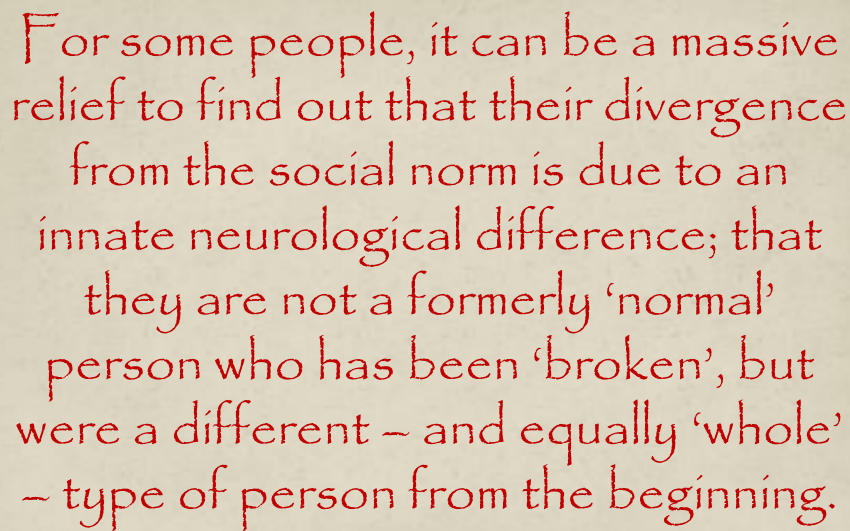
Autistic narratives



Autistic narratives place the autistic individuals as the 'expert' in their experiences, and since the 1990s, autistic activists have articulated neurodiversity perspectives (Arnold, 1999; Sinclair, 1993), which can be argued to fall between disability/impairment and mental illness categories (Graby, 2015). This is important since these 'insider' narratives hold key information for researchers, practitioners and service providers generally (Baggs, 2003; Grandin, 1995; Jackson, 2002; Lawson, 2001; 2011; Murray, 2006a; Sainsbury, 2009; Sequenzia, 2012; Williams, 1999a; b; Yergeau, 2010), and have emerged from a self-advocacy perspective to counter 'a parent-dominated "autism advocacy" lobby' seeking a cure for autism (Beardon and Edmonds, 2007; Graby, 2012; 2015; Waltz, 2007).

A key theme in this perspective is the persistent distress, or psycho-emotional disablement, caused as a direct result of being misunderstood and rejected by a neurotypical-normative society (Reeve, 2004; Reeve, 2015).

This information was important in informing my design frame and methods, and was critical in assisting me to answer my research questions. Autistic people emphasize that an important need in autism research is the recognition that language and communication are a two-way process (Chown, 2014b; Milton, 2012a), and many state that adding visual information to speech is often helpful (Grandin, 1995; Lawson, 2011). As such, it was essential that my method design acknowledged and encompassed the strengths and preferences of autistic individuals.



For some people, it can be a massive relief to find out that their divergence from the social norm is due to an innate neurological difference; that they are not a formerly 'normal' person who has been 'broken', but were a different ~ and equally 'whole' ~ type of person from the beginning.

Graby (2015, p239)

The unique character and experience of 'voice' as the subject of the narrative (Atkinson, 1997) rests against a background of previous silence occupying both a political and epistemological position (Elbaz, 1990, In: Sparkes, 1994). This is evident as autistic narratives are repeatedly ignored (Milton and Bracher, 2013), and narrative purpose in relation to autism is frequently linked to diagnosis and the future of autistic individuals (Beardon and Worton, 2011). However, legislation regarding inclusion of the autistic voice (DoH, 2010a; HMSO, 2009; 2010; NICE, 2010) necessitates exploration of diverse narrative influences, resources and emerging themes (Plummer, 2014). Emerging narratives may improve and adapt, or consolidate, maintain or evade normative

narratives (Plummer, 2001; Squire, 2012), and this is highly relevant to autism research (Milton and Moon, 2012). Riessman (2005, In: Phoenix, 2014) also observes that narratives may be produced due to a contradiction between the real and the ideal, thereby demanding reflection on both narrative sequence and consequence. This is relevant to my second and third research questions in relation to power, context and their impact on identity and wellbeing.

The importance of autistic narratives to my study then led me to consider narratives more widely. The iterative nature of the narrative process is important information for service providers wishing to develop inclusive policies and practice (Luttrell, 2012), and institutions, families, communities and cultures have continually circulating stories about current or past events. The purpose of narratives told for my study may be extremely diverse, and I wished to emphasise the powerful influence of visuals on a story (Waltz, 2012), and this is discussed in the next section.

Visual methods

Assisting people to explore their visual side practically is important in the autistic world and has potential for facilitating communication for some individuals (Lawson, 2011; Simone, 2014). Furthermore, Lawson (2011) argues that an added visual dimension may not only help to counteract

the difficulty with language skills faced by autistic people in respect of forward thinking (prediction and planning) and literal thinking, but it may also help non-autistic people understand the individual and shared worlds of autistic individuals. This view is supported by an e-survey concerning the views of children/young people with epilepsy, where findings indicated a wide range of visual media to be useful for informing others about a disability (Lewis et al., 2007).

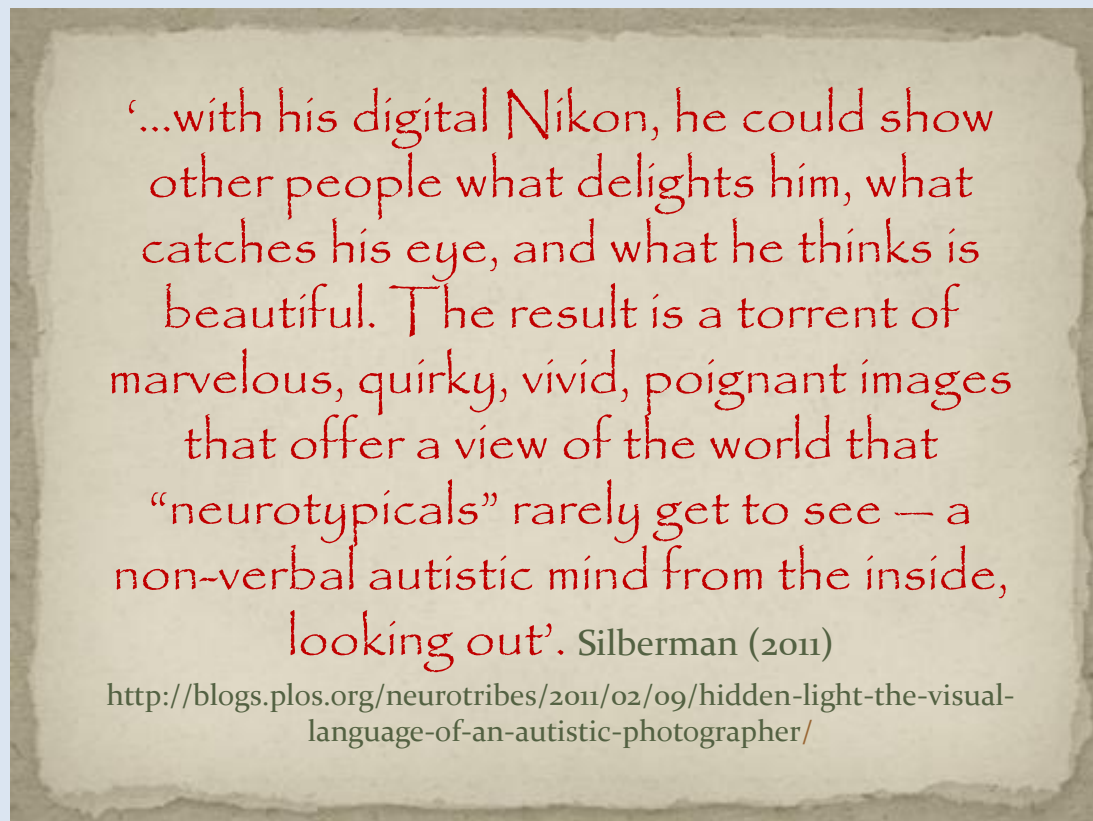
Photomontage

Construction of visual images reflects and permits numerous interpretative possibilities, as evidenced between the visible (vision) and the construction of the visual (visuality) (Rose, 2001, p6), and it has been argued that visual narratives should embrace other narrative genres in establishing their own context, content and meaning (Harrison, 2002a, p108). Gerland (2000b, cited in Sainsbury 2009) emphasizes the importance of self-understanding in order for autistic people to 'make best use of their strengths' (p119), and this is closely linked to the two matters of communication and requirements, so I reflected on the possible benefits of photomontage in the creation of dialogue and resolution of problems between service users and service providers (Kaplan et al., 2007).

Photomontage/collage involves the cutting of ready-made images/text and rearranging them to form a new, seamless image or montage which may inject a feeling of enigma, chaos, trickery or amusement (Ades, 1976). The resultant composite is drawn together using the original cutting and gluing techniques, or by using more sophisticated computer software, although the former has proved more welcoming of time and movement (Shortt, 2012). For me, its beauty as a method is in enabling exploration of a range of creative techniques to combine and juxtapose words and images. This distortion and manipulation of images frequently strike a political or satirical agenda and bends or corrects the truth (Parker, 2011), and the manipulation of images and messages makes photomontage a powerful tool for negotiating and renegotiating narratives and contexts (Jones, 2002). It allows us to take risks, engaging and re-engaging in the activity over different time periods, lending itself well to the exploration of issue-based work and diverse voices (A.C.T., 1998). As such, it may lead the listener, reader, or viewer into new unexplored territory. Today researchers and audiences wish to move beyond the image and engage in contextual questions, ponder the process of production, on rejected content and reasons for decisions around this (Winston, 1998), and this held potential for exploration of my research questions.

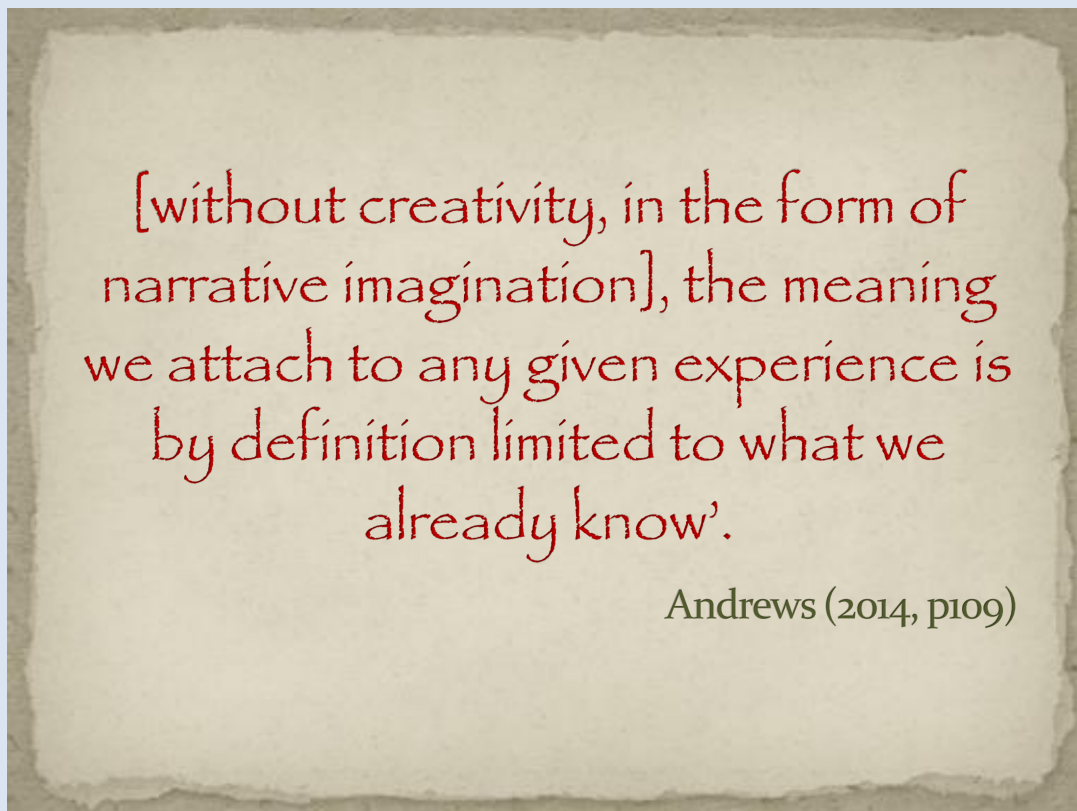
Critically, as a tool that underpins photomontage/collage, photography is

popular among autistic individuals, not only as a tool for expression, but also as a means for demonstrating and utilising skills, as is shown in the case of a 20-year-old man, Sargent:



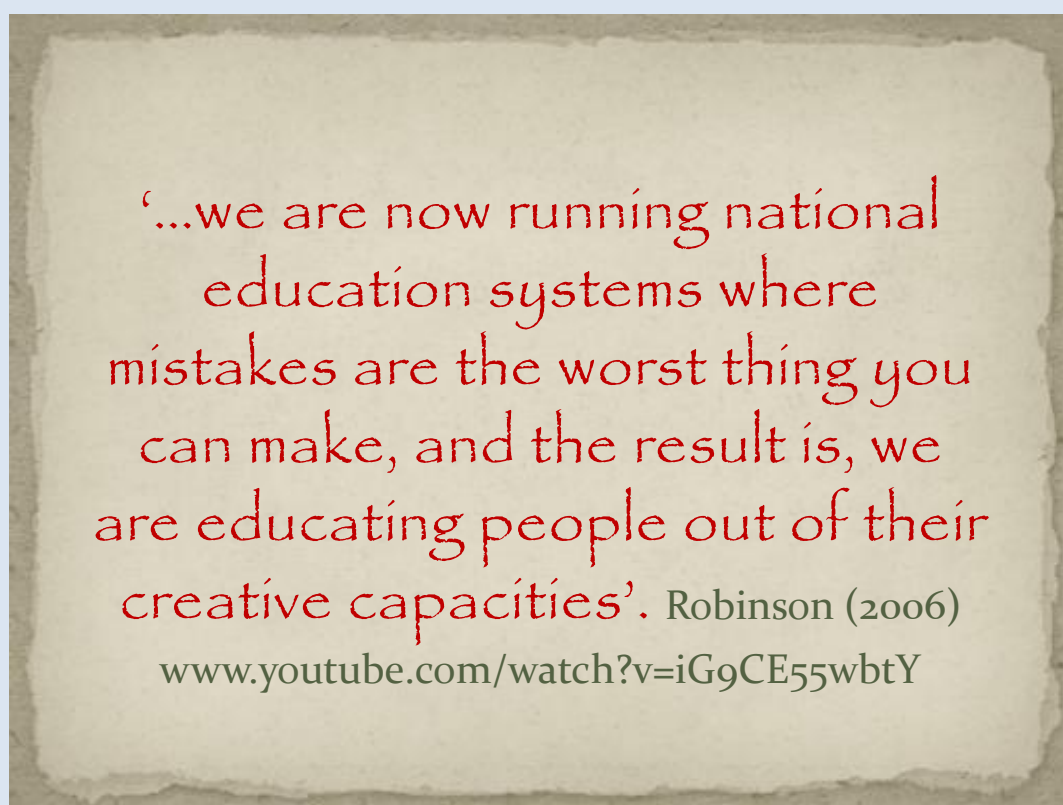
An example of the possible use of photographic images for my study was also shown through exploration of the sites of meaning making (Wiebe, 2013), and since context is a key part of understanding a narrative (de Fina and Georgakopoulou, 2012), this was another key message for my design and would impact on all my research questions.

Summary



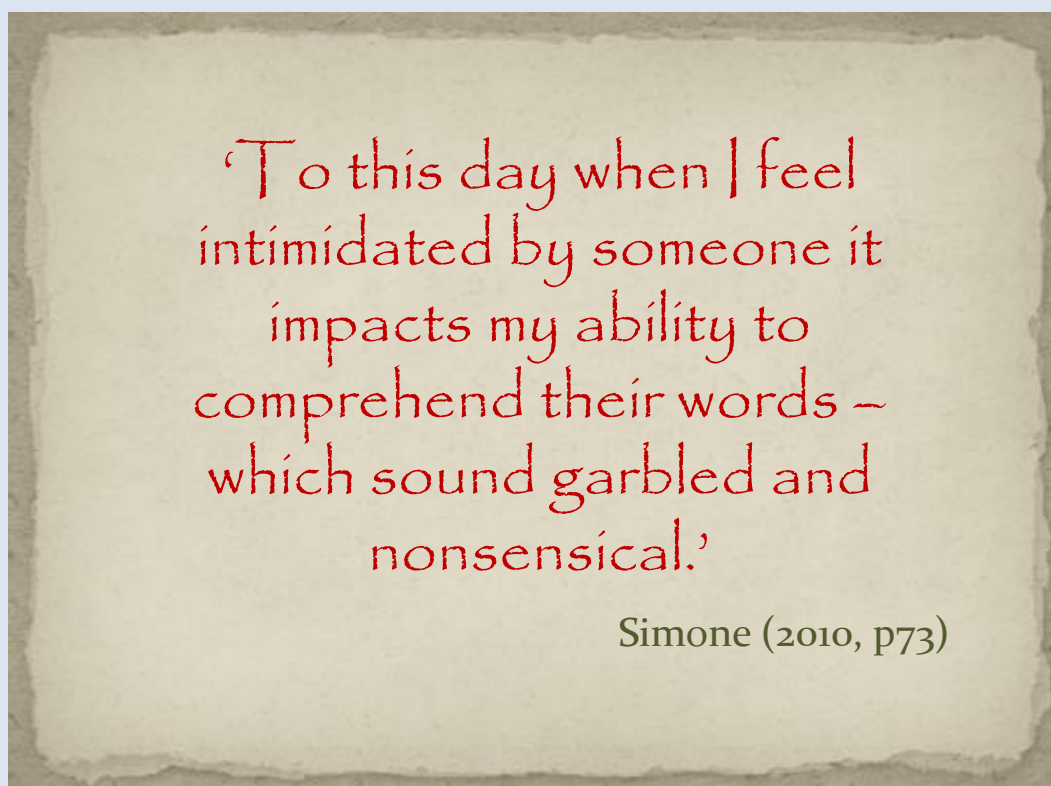
Method design required creativity in order to access the views of those with communication differences/difficulties (Nussbaum, 1997), and possible challenges engaging with autistic individuals were a critical ethical consideration at this stage (Section 4.7). As someone from an arts background, I consider creativity to be an essential feature in the design of a workshop or any activity, as it assists memory, and approaching a task in a different manner taps into our natural creative flare (Oliver, 2010), and I felt that this would be particularly appropriate with the individuals in my study.

For this reason, whilst I chose traditional methods for my pilot, I was more creative in their design for my main study, which embraced preferred methods of communication as expressed by various autistic individuals (playing games, visual activities and being asked their views on matters important to them). In addition, I reflected on recommendations made by Parsons et al. (2009) looking at best practice in the education of autistic people, the more naturalistic approach emphasised by Madriaga et al. (2006), and the NAS guidelines (Powell, 2002), which mentions a lack of creative opportunities for autistic individuals to express themselves.



By failing to engage with diverse communication preferences, the voice of many is silenced and 'question and answer formats may be more

constraining than narratives or the use of statements' (Lewis and Porter, 2004, p195). Therefore, involving autistic adults in the design of methods to access their views was fundamental to maximizing opportunities for their engagement. Embedded in this was the right of a participant to remain silent, yet have this interpreted and reported on in a way that acknowledged that it may not be 'neutral' or 'empty', but expressing many views (Lewis, 2010; Lewis and Porter, 2004).



Silence used on a daily basis is filled with moments of reflection, planning, indecision, relaxation, disassociation, concerns and enjoyment, and this is arguably no different to similar moments experienced in a research situation. Relevant to my third research question are observations by Lewis (2010) and Lewis and Porter (2004) on the relationship of the researcher and participant, and how moments of silence are managed in

terms of their emergence, control and interpretation. This work had important messages for my research in terms of recognising challenges faced by autistic individuals, and which may subsequently result in silence (Sequenzia, 2012).

Having explored some methods to explore and collect data regarding autistic people's experiences, I needed to attend to issues that may facilitate or impede this process. This next section reviews the wider ethical issues impacting on my study as well as in terms of working with autistic individuals.

4.7 Ethics



Figure 58: Ethics

Following approval of my application for ethical review by the ethics committee at the University of Birmingham, I reflected on how research ethics regarding vulnerable people need to be discussed beyond this, to explain the application of specific ethical protocols. These are now discussed below.

Consent, right to withdraw and confidentiality

As I wished to place autistic participants in my study as the expert in their experiences to contextualise their voice and provide more robust data (DoH, 2010a; b; UN, 2006), it was critical to obtain the consent of individual participants. Therefore, their understanding of the consent process was critical, particularly in relation to the double-bind tension between 'giving consent' and 'providing information', where improved transparency in both process and practice is recommended (Larkin et al., 2009). Consequently, emphasis has also been placed on consultation with user groups, placing individuals as key players in decisions impacting on them, and also regarding staff training (Beresford, 2013a; b; Larkin et al., 2009). Listening to the voice of autistics on this issue is crucial in shifting the balance in autism research (Milton and Bracher, 2013).

Whilst competence to consent generally arises in relation to mental health treatment (Larkin et al., 2009), it is evident that different communication styles may well impact on this area (Rabiee and Glendinning, 2010), and

this is relevant to my study. In addition, participants needed to have an option to withdraw from the study at any point, to be reassured that this would not impact on their support, and to be informed that any information provided by them would be treated as confidential. Whilst staff working with participants were involved with all aspects of this process, with the aim of enabling individuals to take time to reflect on and process information and respond accordingly (Ridout et al., 2011), the potential impact of this will be discussed in Chapter 7.

Understanding of autism and neurodiversity

Recognition of the wide range and variation of challenges experienced by autistic individuals (see Chapter 3) was essential to the design of my methods as was situating the autistic person as the expert voice in their experiences. This addressed the view held by many autistics, that anything they do as an autistic individual is taken by non-autistics to be an example of autistic behaviour more generally (Arnold, 2013).

Disabled individuals are often at the mercy of inaccurate reports written and decisions made by practitioners and researchers as a direct result of their voice being ignored or misunderstood (Milton, 2011b; Milton and Bracher, 2013), and this impacts negatively on wellbeing and access to relevant support and services (see Chapter 2). Therefore, meaningful communication between autistic and non-autistic individuals is

fundamental to the provision of inclusive services and opening up of relevant opportunities, and my method design needed to embrace this point.

Communication styles

A person familiar to the autistic participant, and who they wish to accompany them, may be useful in facilitating communication between the researcher and the autistic individual. A study exploring successful engagement with young people highlighted the importance of selecting appropriate methods with all young people (Hibbert, 2005). However, there is also a need to reflect on the influencing of the research agenda/data as regards ways in which participants choose to participate in, or are selected for a study (Mauthner, 2000; Miller and Bell, 2002).

My study supports the view voiced by many autistic individuals, that timing is directly related to different processing (Lawson, 2011; Murray et al., 2005), and as an individual, I reject the view that time is a factor indicative of ability/inability (Baron-Cohen and Wheelwright, 2004). Therefore flexible methods, which welcomed participants' different processing and performing times, were essential to my design in order to improve engagement, accuracy and effectiveness.

Anxiety

Heightened anxiety experienced by some autistic individuals when dealing with new people, situations, and activities may be subtle or more overt, and requires provision of a quiet space and time to process sensory and social information (Hodge, 2014). Additional support to reduce anxiety and facilitate meaningful communication may include information sent prior to the research, including a photo of the researcher, choice of venue and a familiar person present (Muller et al., 2008). Important too was the acknowledgment that diverse sensory and social challenges experienced by autistic individuals do not reflect a lack of desire to communicate (Lewis, 2010; Sequenzia, 2012), but that a failure to address this can result in skewed data as an individual may subsequently be unable to engage in an activity (Muller et al., 2008).

Importance of involving autistic people

Choosing a research tool which permitted time to process information and manage feelings of anxiety regarding the research process and expressing of their views was key to respecting the challenges faced by individual participants (Chown and Beavan, 2012; Murray et al., 2005). In addition, findings by Williamson et al. (2008) were of interest to my study as they indicated that approval is generally considered to be more important to autistic adolescents than their competencies.

It has been argued that social research needs to involve service users at all levels of the research process in order to be of any value in terms of enabling positive change in the lives of disenfranchised/marginalised individuals (Tew et al., 2006). Valuing the perspectives of individuals on whom services impact is considered key to establishing appropriate services (Billington, 2006), and is central to the Autism Strategy (DoH, 2010a). However, the diverse preferences employed by individuals to express themselves should be acknowledged, particularly around times of transition (Cameron and Murphy, 2002).

Referring to individuals with little or no speech, Preece and Jordan (2009) acknowledge the 'potential to attribute opinions to individuals' (p11). Consequently, misinterpretation of actions/speech can occur as can the imposition of meanings different to those intended by the individual, and lends additional weight to my decision that my methods should be informed by the preferences of autistic individuals. In addition, issues of *inclusiveness* and *fairness* have been shown to be central features of the method preferences expressed by children and young people (Hill, 2006).

Active involvement in research

Autistic people should be able to engage in more opportunities to express their view (Arnold, 2013), yet reviews of research have highlighted a gap in accessing the voice of autistic people and in including them in research

concerning their requirements (DoH, 2010a; Parsons et al., 2009). However, studies show that young participants prefer methods involving interaction with the researcher and an assurance that a response to their views would be provided if they engaged in the process (Hill, 2006). Furthermore, preference regarding use of a group activity or individual work has been highlighted as requiring careful consideration (Punch, 2002).

A study by Tew et al. (2006, p7) suggests that service user involvement in the design and implementation of research is more likely to result in openness and clarity from participating service users respondents. One study involved 18 autistic adults in the design, implementation and analysis of the research (Muller et al., 2008). Semi-structured interviews, carried out in two phases in the participants' homes, explored social experiences and effective supports and strategies for improving social connectedness and alleviating social anxiety. Findings pointed to the need to include the autistic voice in service development as it may lead to a more accurate picture of their requirements.

Although the above findings may include negative perceptions held by autistics as a direct result of being given support which fails to embrace diversity (Humphrey and Lewis, 2008), inclusion of these views are essential in order to celebrate and tap into the wealth of skills and

potential contributions of autistic people. Researchers and service providers need to address this (DoH, 2010a) if policies and practices are to redress the current imbalance.

Mixed media research

The focus of the research agenda and involved stakeholders is critical in decisions around the inclusion/exclusion of data (Mwale and Spiegelhalter, 2014; Pellicano et al., 2013). Effective collaboration plays a key role in the inclusion of information and provision of feedback to participants to avoid any negative impact on wellbeing (Mwale and Spiegelhalter, 2014), as does confidentiality (Robson, 2002).

Visual data

The 'ethics of seeing' must respect issues of confidentiality regarding both artist and institution (Riessman, 2008). As my original plan was that participants select their own visual material such as photos and magazines of their choice, reflecting their interests and key moments in their lives, I needed to be careful that anonymity would be maintained.

A further point in relation to ethics and visual data concerns the power of an audience over interpretation of the media text. Visual text can be diverse and include text, collage, photography, advertising and

magazines, among others (Gauntlett, 2008). The impact of power, therefore, may also be diverse.

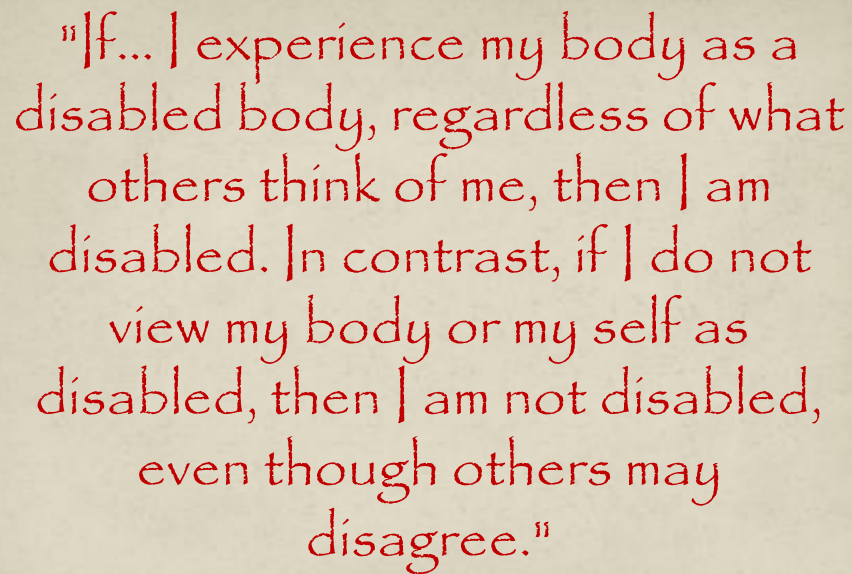
I now discuss issues relating to the validity of my study.

4.8 Validity

Validity intertwines with ethics and requires particular attention regarding participant sampling concerning the user voice of vulnerable people, and provision of information concerning the research process and consent (Mauthner, 2000; Miller and Bell, 2002).

Validity and the insider-outsider experience

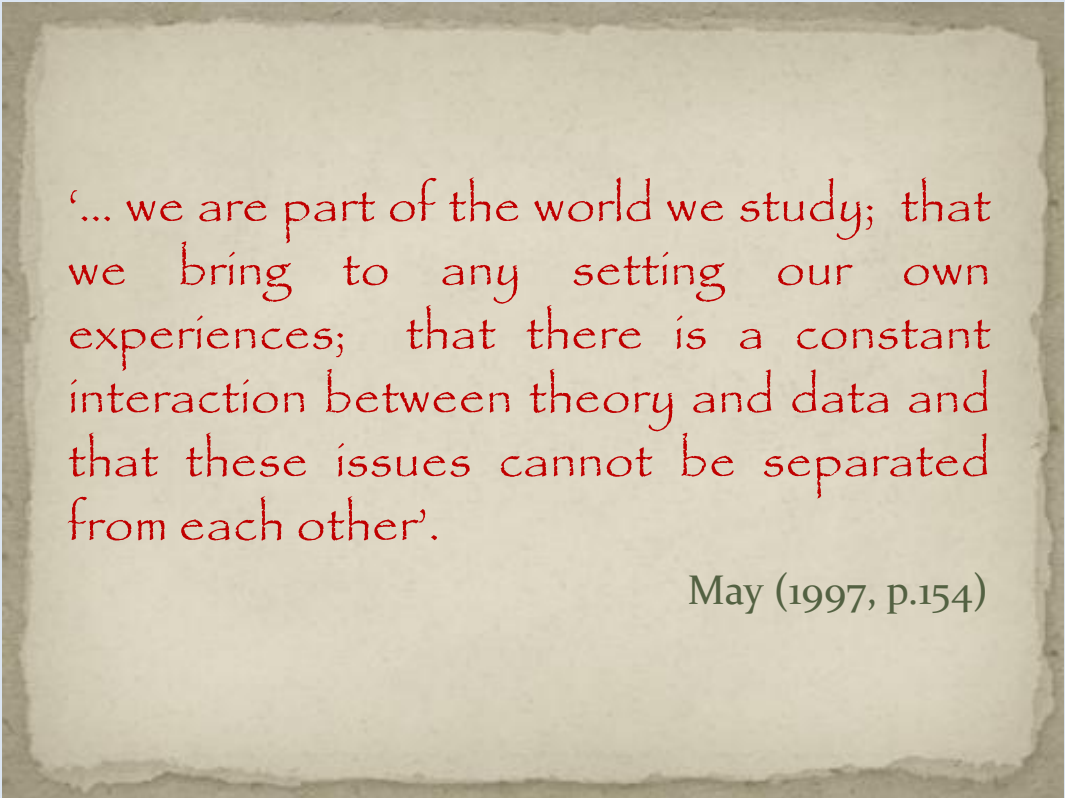
My study places the autistic participants as expert in their own experiences, and the following quote by Gabel, talking about self-defining, expresses the right of individuals to express their identities and experiences as they wish regardless of outsider views. This concept is critical to my study since it links with disability identity and the 'reappropriation of 'autism' from a label to an identity' (Graby, 2012).



"If... I experience my body as a disabled body, regardless of what others think of me, then I am disabled. In contrast, if I do not view my body or my self as disabled, then I am not disabled, even though others may disagree."

Gabel (1999, p.42. In: Graby , 2012)

Readers of my research might question the accuracy of narratives provided by the autistic participants in this study. However, the above argument would query the right of outsiders to question the expressed identities, and consequently the experiences, of insiders. Essentially this would appear to validate the experiences of autistic participants and would fit with my interpretative approach.

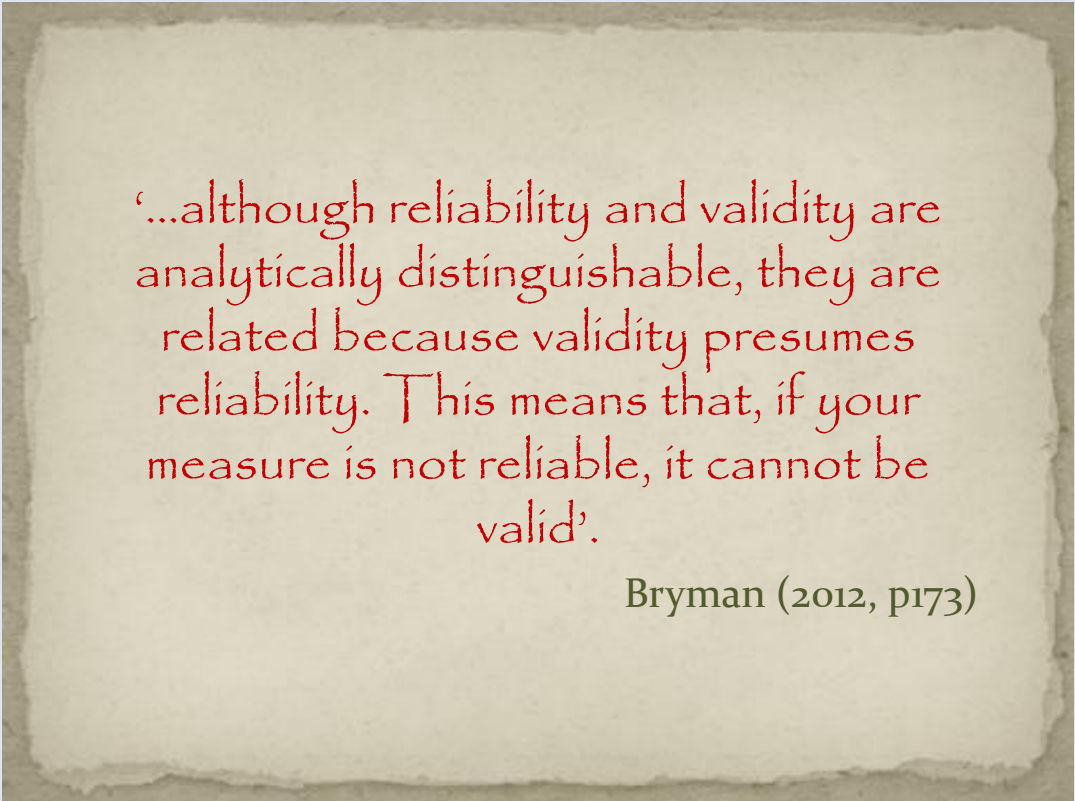


‘... we are part of the world we study; that we bring to any setting our own experiences; that there is a constant interaction between theory and data and that these issues cannot be separated from each other’.

May (1997, p.154)

As my standpoint was one of an insider-outsider, this was arguably the greatest supporting factor in favour of the validity of the interpretation of my data (Gabel, 1999 In: Graby, 2012). This position places my study as slightly distinct from contemporary research including the voice of autistic people as researchers and researched. Nevertheless, in placing the voice of autistic participants as the expert in my study (Grandin and Barron, 2005; Hacking, 2009; Milton, 2011b; Murray, 2014; Murray et al., 2005; TAP, 2014), I argue that both standpoints regarding autism have a valid and long-awaited contribution to make towards balancing the arguments put forward by positivists.

Validity and methods



‘...although reliability and validity are analytically distinguishable, they are related because validity presumes reliability. This means that, if your measure is not reliable, it cannot be valid’.

Bryman (2012, p173)

The interpretative nature of my study, informed by an exploratory phenomenological process, required that the experiences, individual or collective, of participants were accepted for what they are (Larkin and Griffiths, 2002; Larkin et al., 2006; Reid et al., 2005). My planned triangulation of methods provided robust contextualised narrative data, and whilst narratives are susceptible to change, this does not necessarily render them invalid (Andrews, 2013). Consequently, triangulation of data would also validate the contribution of the narratives in my study and reflects my positionality.

My approach required reflection regarding potential researcher bias (Robson, 2002, p172), and I was concerned that my methods would

provide sufficient opportunity for individual participants to express their views. In this respect, the appropriateness of my methods has been commented on by researchers influencing my study. As such, Chase (2008b) regards questionnaires and narratives as belonging to oral or written enquiry covering life histories or stories, Luttrell (2003) also places visual methods, such as photomontage, as a valid and reliable narrative in the moment that it is told. Although it was possible that the process, resultant image and audiencing of each would be potentially different, images produced would be presented in the raw, un-interpreted form prior to my interpretation(s), as this would allow readers to interpret the visual or written narratives of autistic participants for themselves (Luttrell, 2003). The subsequent location of these narratives in a wider context encompassing a diversity of narratives (Harrison, 2002b) provided additional markers against which to compare stories.

Methods for data collection can impact directly on motives for participating in or resisting inclusion in research, and this may affect the reliability of data collected (Miller and Bell, 2002). Therefore, I decided that the triangulation of methods was crucial in order to embrace the different challenges and communication preferences of autistic individuals (Arnold, 2013; Hodge and Chantler, 2010; Lawson, 2011; Milton and Bracher, 2013; Murray et al., 2005; Sequenzia, 2012). With a historical lack of opportunities for autistic people to be involved in research processes (Jones et al., 2008; Parsons et al., 2009), I argue that

researchers should allow autistic individuals to speak for themselves, Consequently, my framework lends itself well to identifying and discussing themes important to autistic individuals and exploring how these interact.

Whilst my approach places the individual as the expert in their own reality, the inter-relational dynamics between disabled and non-disabled individuals participating in research also deserves consideration (Tregaskis, 2003 in Goodley and Lawthom, 2005). This is because they may feed a false perception of co-production and inclusion (Chapter 2.1). Maxwell (1992) raises the notion of threats to validity, and of importance to my research was the danger of a threat to the internal validity by the imposition of a framework of interpretation on the data. Therefore, I reflected on the advantages of mixed expressive media, and the various possibilities available to present my data (Chapter 5).

Validity and the case study

Whilst my case study is context-specific, and my research questions were explored with adults who accessed a specific support service, findings may be generalisable both across and within settings (Bloor, 1997). In addition, replicability of my methods may assist in the generating of theories and themes which may be similar or different, whilst constructing a detailed picture of autistic experiences.

The 'alleged deficiency' of the case study (Flyvberg, 2004) found that whilst criticism points to researchers seeking to note findings that support their own subjective experiences, thereby making their study less rigorous (Robson, 2002), this can be said to be true of all methods. My study counteracts this by placing the autistic voice as the expert in their experiences and recognising my own insider-outsider positionality throughout my data analysis (Chapters 5 and 6). In summary, the iterative interactive manner in which my study gathered and triangulated data aimed at establishing a meaningful process. This in turn offered a fresh perspective on this area of study, namely the different impact of an insider-outsider approach.

I now discuss limitations of my study.

4.10 Limitations of the Study

These relate mainly to restrictions imposed as a result of this being a part of a wider evaluation of a support service for Adult Autism and Asperger Service and IDS 16-18 Autism Pilot. Main limitations related to the data collection period specified by funding obtained through Aiming High for Disabled People. This manifested itself in the following ways:

Pressure on staff: service evaluation places a pressure on staff to perform well and report positive results. Consequently, in over-reporting or misreporting the positives, the voice of the individuals that a service is

designed to support is distorted or, at worst, even silenced. It is difficult to assess to what extent, if any, this occurred, but it is an aspect worthy of reflection.

Support staff for the main study, were very much involved in assisting the researcher to contact participants and to support them in answering the questionnaire. The main study sample was selected from people accessing the support service evaluated (Ridout et al., 2011), and this may have resulted in some element of pressure put on them by support staff, whose work was being evaluated. Nevertheless, the findings speak for themselves, and readers of this research, whilst being aware of this potential limitation in respect of authenticity, need to draw their own conclusions.

Time: a slower start-up to the evaluation occurred due to staff recruitment difficulties experienced by management running the IDS 16-18 Autism Pilot. Although this time was used to submit the application for ethical review, design and pilot the research methods and plan the data collection, the delay meant that autistic people accessing the service had considerably less time to engage with the methods of data collection.

Another factor, therefore, which arose related to anxieties faced by some participants, and potentially affected both validity and reliability as support was required to engage in the research. In addition, support was often needed in respect of understanding questions asked, and one of the

participants in the case study had to rely on their support worker to write their answer. This support may have introduced an unintended bias in the way support staff read and explained information, but the triangulation of data sought to address this point and provide various opportunities for individuals to engage with activities. Support was also needed by all participants doing the photomontage and the narrative diary, but my framework embraces an interactive process between researcher and participants in producing data.

Sample size: although sample size is often considered to be a limitation of case studies (Robson, 2002), this has already been discussed, and is not considered a matter of concern for this study. That said, it should be acknowledged that individual experiences may or may not be generalisable across a wider sector of the autistic community, and comparison with findings from other studies would be useful in this respect.

Access to sample: the majority of the sample contacted for the purpose of evaluating the support service from which my sample was purposively selected, required support to access methods of data collection. With a need for confidentiality, access to the sample was via support staff (who sent the questionnaires out via their mailing lists), and the same staff were also involved in providing support to the sample so that they could engage in the method(s) of their choice (questionnaire/narrative diary/photomontage). The sample group for the evaluation was of a wider

age range than that for my research, and only two support staff were available to provide support for up to 80 individuals in order to maximise response rate. It is reasonable to assume, therefore, that with a response rate of 9%, several people would be unable to engage in the evaluation (and consequently my research) due to a low staff to service user ratio.

Participation: my data analysis needs to acknowledge that non-participation, or silence is also a form of communication (Lewis, 2010; Mauthner, 2000; Plummer, 2014), as the methods chosen may have been accessible to some, but not suit the preferences of others. It is difficult to comment on the real reason underpinning lack of participation, but this is an area for further exploration.

Methods not fully tested: as a result of time restrictions and support required by service users to engage with methods, the narrative diary was not fully explored and provides an opportunity for further investigation. That two people did choose this option indicates potential for future research.

The introduction of the narrative diary by support workers led to a more linear chronology of events. However, this complimented the collage process, which entailed the features of narrative construction, deconstruction and re-construction. This process of allowing authors to move backwards and forwards between narratives in the storying of their

experiences became one which I also adopted in trying to make sense of their experiences.

Dissemination of information: as the funding for the service evaluated was time-limited and some key members of staff had changed or left, it proved difficult to contact participants since this had always been done through staff. Consequently, their feedback was not provided and I was not able to discuss any concerns they may have had. The implications for this are discussed in Chapter 7.

Summary

This chapter has reviewed my methodology and critical influences on it. Critically, methods were informed by autistics and piloted and adjusted before implementation in my main study. However, I have also discussed some key limitations of my approach.

The following chapter presents the three individual case studies and analyses the data in respect of each.

Chapter 5: Three Individual Case Study Narratives

5.1 Introduction

This chapter presents three narrative case studies comprising diverse narrative genres. The presentation of the narratives is done in chronological order to enable the reader to view the initial narrative genre explored first, and as each layer is peeled back, the reader will be exposed to the array of possible stories that have been and could have been told.

5.2 Narrative Case Studies

The case studies I have selected to explore were chosen as they illustrate the perspectives of three individuals differently involved in a regional support service for autistic adults and the pilot support for young autistic individuals. The case studies concern:

1. Sophie, a teenage girl in transition to adulthood, who had engaged in the narrative diary and collage aspects of the study;
2. Michael, a young man whose views had an impact on the funding of a support service for autistic adults, and who produced his own narrative in addition to participating in the collage activity; and
3. Peter, a young man attending the support group for autistic adults, who produced a mind map of his requirements.

5.3 Chapter Structure

I now take the reader on a journey exploring these narrative case studies. I review the production of each narrative and analyse it in relation to my research questions and within my theoretical and analytical framework, which blends IPA, narrative analysis (dialogic-performative and visual) and critical discourse analysis. My presentation allows me to refer back to my stance on the purpose of social theory, and explore how each autistic individual describes and explains their experiences.

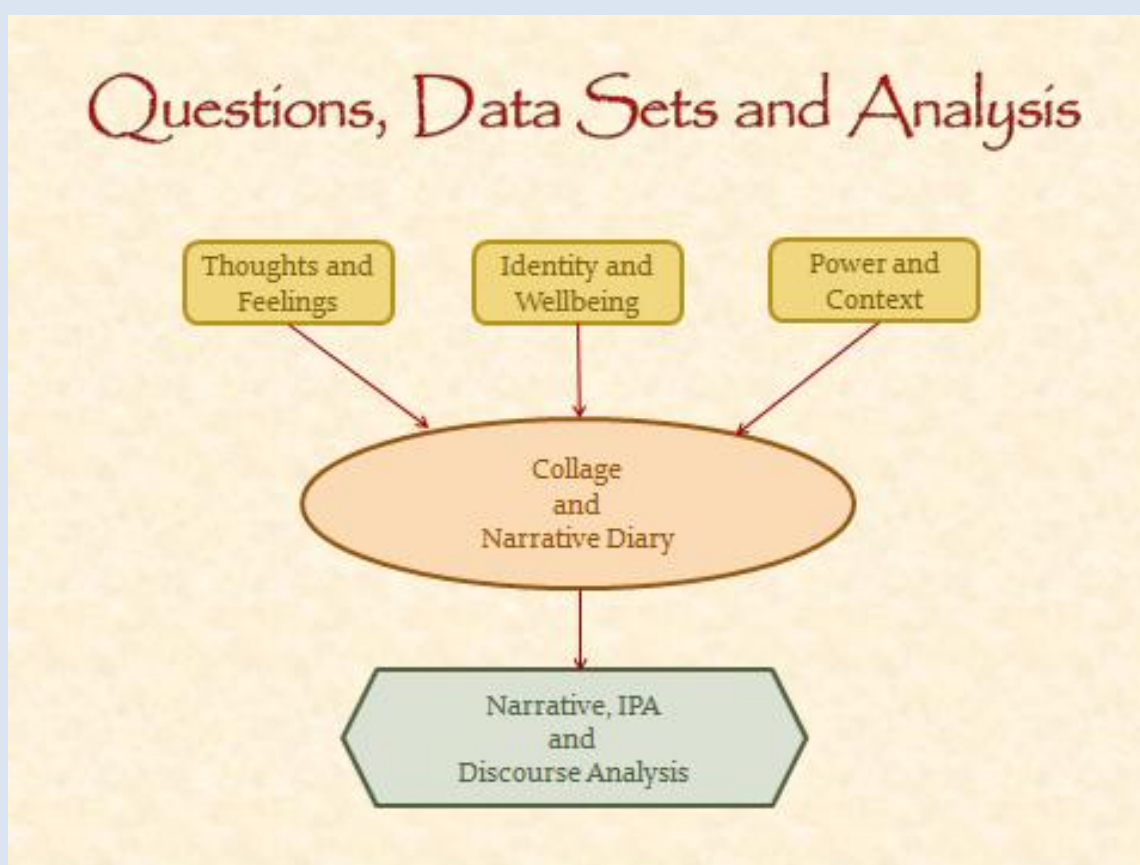


Figure 59: Matching questions, data sets and analysis

In addition, I used four key sites of meaning-making – process, image, audiencing and turning points, with discourse occurring throughout - to unravel my data:

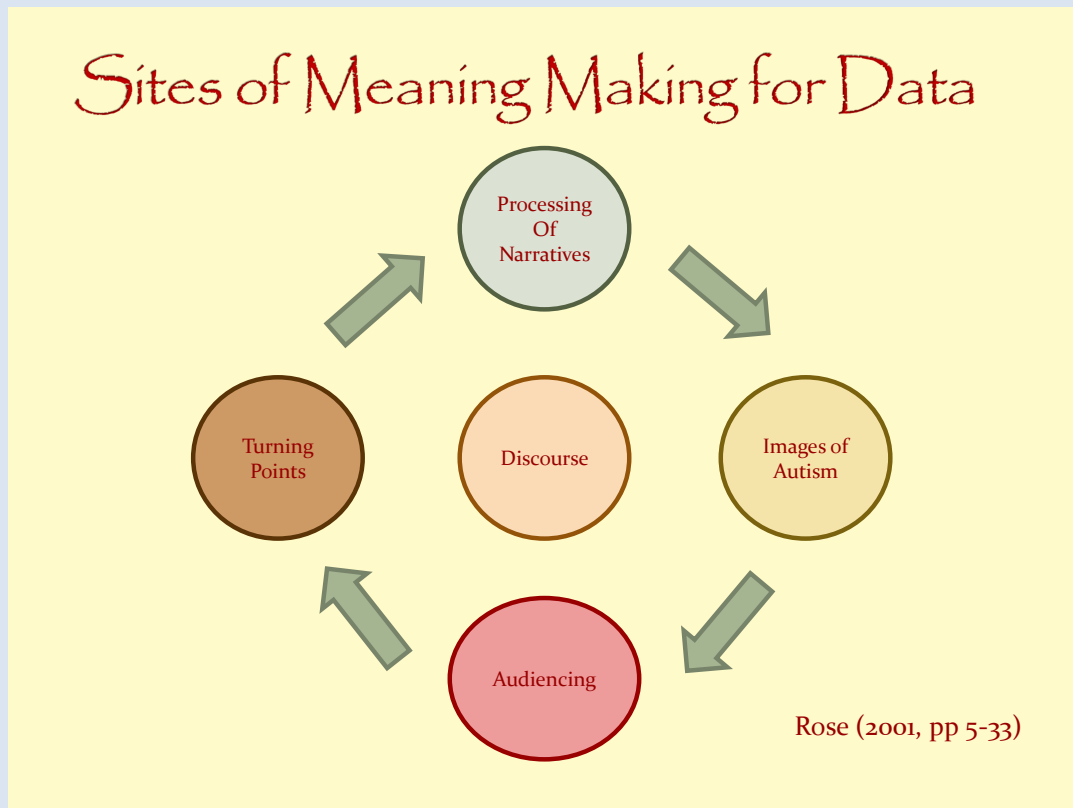


Figure 60: Sites of meaning making for data sets

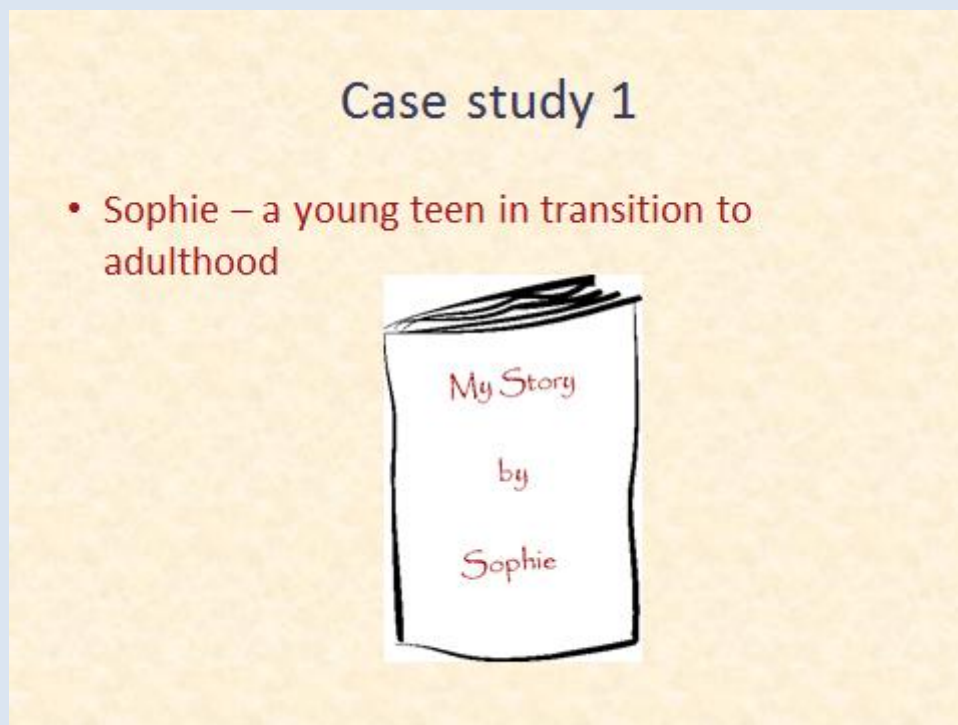
The sites paid attention to the specific areas addressed by my research questions, namely thoughts and feelings, identity and wellbeing, context and power, and discussion was placed within my theoretical framework. I chose to use these specific sites of meaning making as they allowed me as the researcher, and new narrator in these narratives of autism, to consider each from a number of perspectives. Critically, I argue that this is fundamental to the progression of an inclusive agenda for autistic individuals.

I present each case study separately, discussing for each:

1. the context in which the narratives took place, since these occurred in diverse settings;

2. the narrative genre(s) engaged in by each individual, and the process by which they were differently adapted to story their experiences;
 3. the narrative image, or data, emerging from each data set or narrative genre;
 4. a visual and written summary at the end of each narrative genre, presented using my research questions to provide a structure;
 5. the accompanying narrative from a parent (if any), highlighting themes raised under headings raised by my research questions;
 6. possible interpretations of how the three authors, Sophie, Michael and Peter conceptualise their experiences. This is presented at the end of each case study using my research questions as a structure.
- I provide a visual presentation of certain narrative components within and across the genres in an attempt to show how, as an audience, I can choose to listen to different parts of each individual's narratives to formulate my own understanding of their experiences. This last section is a new contribution to this field, and one which highlights opportunities and barriers to listening to new stories.

Narrative case study 1: Sophie



Context

The first case study that I present is about Sophie. Sophie's narratives provided an example of issues key to developing appropriate and relevant services for a teen in transition to adulthood, and where support provision also moves from children's to adult services. More importantly, these issues are those expressed by the autistic teen herself. There are several members of her immediate family who are disabled, and Social Care was involved to provide support. As an individual, Sophie was receiving 1:1 support to help her in her journey to adulthood, and this was characterised by regular activities to help her build her confidence, develop independent living skills and to assist with making choices about her future. Sophie had previously completed a questionnaire to obtain her views on the autism support service she was accessing. The form had also

provided options for her to take part in other narrative methods namely, a narrative diary and photomontage, specifically with the aim of enabling her to describe and explain her experiences in more detail. Sophie was interested in visual arts, studying this as a part of her college course, which she was about to complete. She decided, therefore, to story her experiences using both of these narrative genres.

The context for the diary production contrasted with that of the collage production, as the former concerned Sophie and her support worker. In contrast, in the latter I was present as an unfamiliar person, and Sophie's mother and support worker were present as familiar people. The collage workshops took place in a quiet room in a staff-controlled social care building in clean surroundings in a green area within the town, with me, her mother and her support worker present. The mood was really peaceful throughout, and I had previously decided not to video sessions so as not to disturb the natural dynamic that emerged between me and Sophie.

Narrative diary

Process

The diary was produced during 1:1 work between Sophie and her support worker. Due to the demands on Sophie's family and staffing shortages, I explained the narrative diary activity to Sophie's support worker for her to

introduce to Sophie as a medium for storying her experiences. The support worker later told me that she had introduced the activity and helped Sophie in the production of a succinct narrative text.

Image

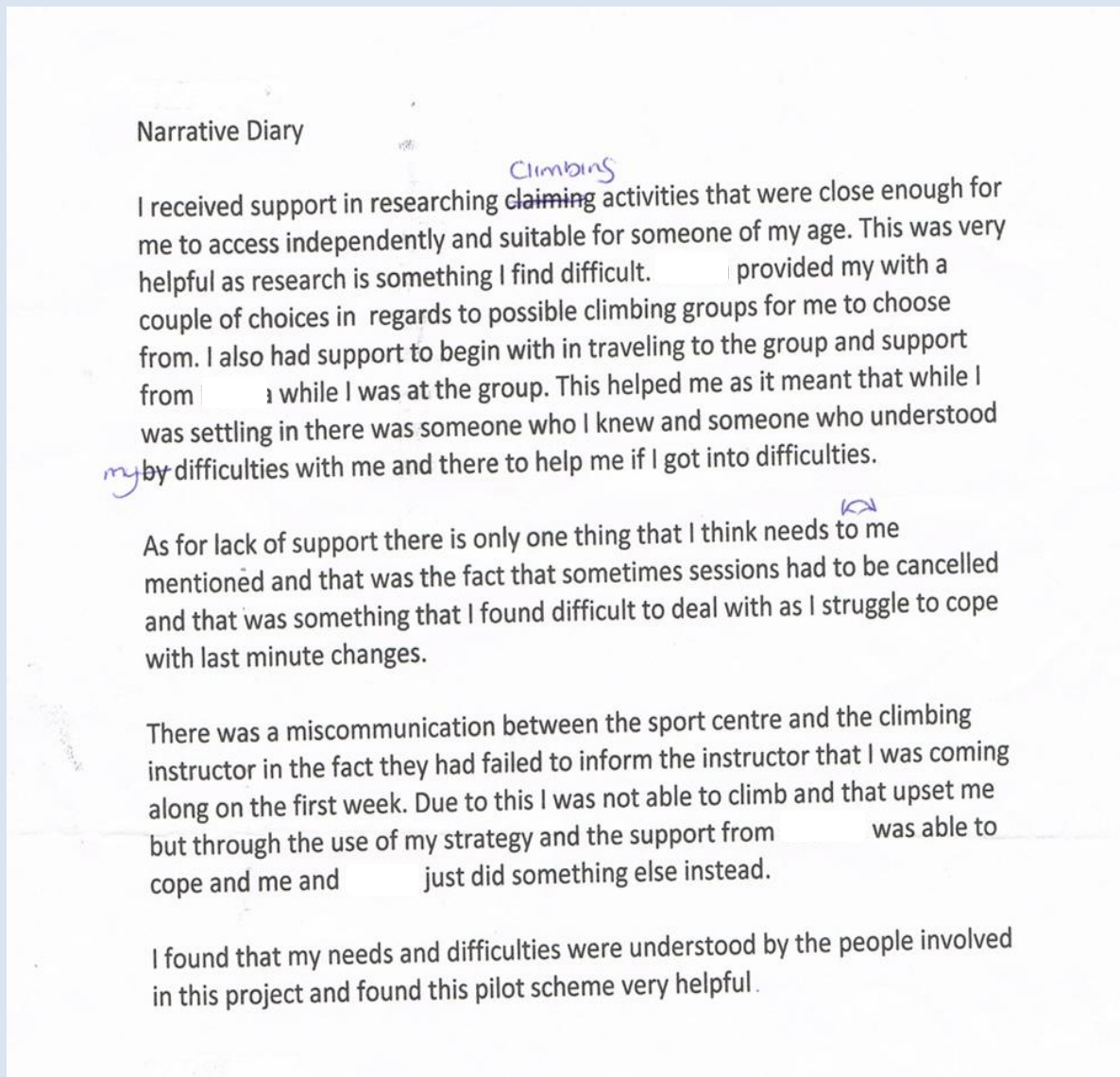


Figure 61: Sophie's narrative text

The first paragraph vacillates between language which suggests a distancing from the storyline, and that which indicates a more personal engagement with the narrative. The support worker is mentioned twice in the first paragraph, but there is no mention as to how the decision was made to pursue climbing activities, and there is a lack of information as to how the suitability of these activities was determined or by whom. In addition, the process of researching is not detailed in this image. This paragraph introduces areas of support provided and their relevance to Sophie.

As this text moves forward, Sophie creates a sense of space, and this is evidenced by the change in language in the second paragraph. In stating 'the one thing that needs to be mentioned', she is not making it clear who needs to mention this fact, but simply that it requires stating and I am again left to wonder why this might be the case. In storying the impact of last minute changes leaving her to struggle, the textual narrative provides me with no information about the effect that this has on her.

The third paragraph also introduced a sense of detachment and space, and indicated that discourse was going on around her about her support, but which did not include her. Sophie's lack of agency is linked in the text to the negative impact that poor communication by others has on her, and this is important in the light of literature pathologising the

communication skills of autistic individuals (ANI, 2000; Bagatell, 2007; Beardon and Worton, 2011; Chown and Beavan, 2012; Murray and Lesser, 2006). Again, the phrasing of 'a strategy', 'my support' and 'enabled me to cope' with less detail, lack agency and depersonalise her experience.

The final message in Sophie's narrative diary is somewhat confusing for me. As with the first paragraph she begins with 'I'. However, she now moves from a position of naming one specific support worker several times to a summary of support provided by several workers and a pilot project. This final section related to the context in which the data was collated, addressing the agenda of the pilot support service being evaluated by ACER to establish future funding potential (Ridout et al., 2011).

Summary of Sophie's narrative diary data

Feelings and thoughts

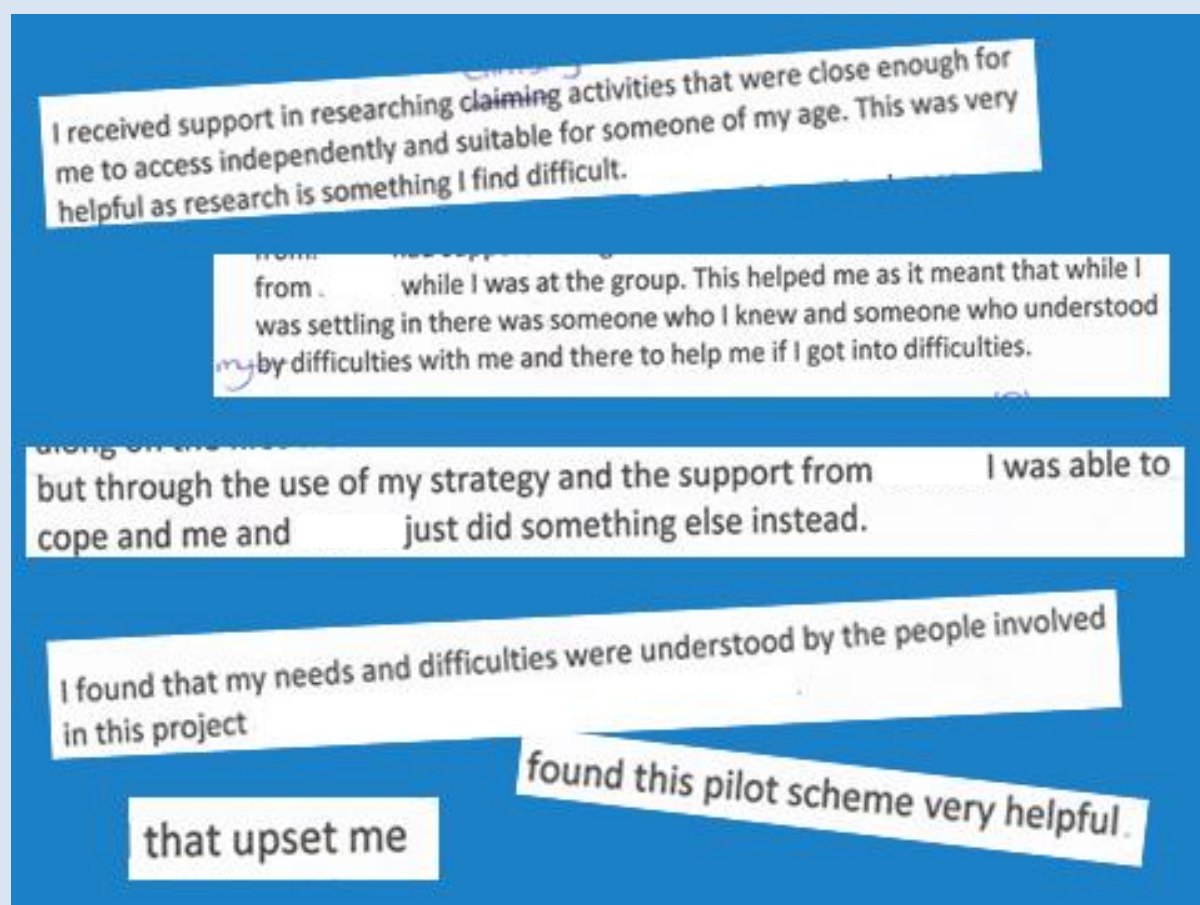


Figure 62: Feelings and thoughts data from Sophie's narrative diary

The actual data contained in Sophie's narrative diary regarding her feelings and thoughts pointed to some difficulties, which upset her, and also that specific aspects of the activities engaged in had been helpful. The authenticity of Sophie's voice is questionable at this stage, but as one narrative layer, it is important and can only truly be scrutinised in the fuller picture of other narratives provided by Sophie.

Identity and wellbeing

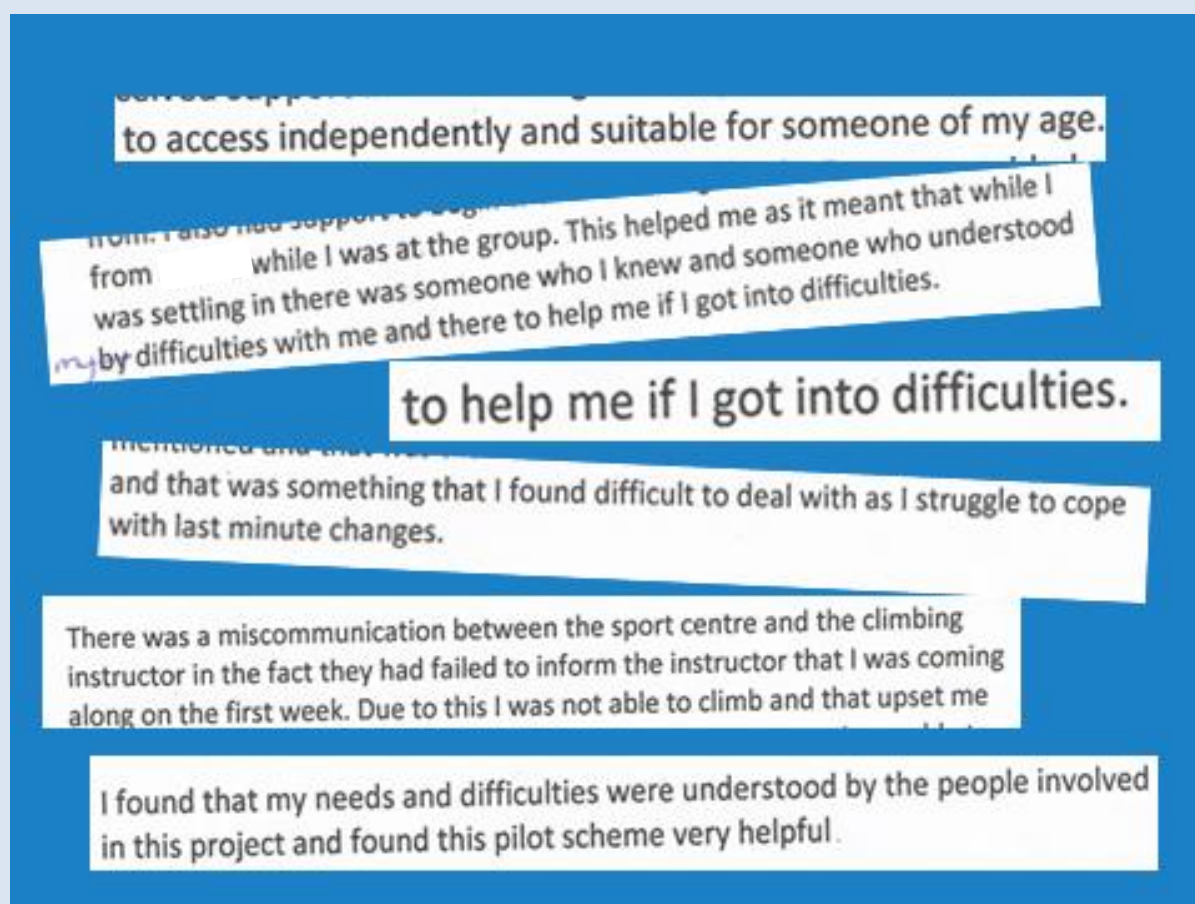


Figure 63: Identity and wellbeing data from Sophie's narrative diary

The data provided in the narrative builds a picture of someone who faces obstacles in life, where support from empathetic others is helpful, as these may not be understood by some. As an audience, I can also determine that issues relating to the building of independence and accessing appropriate activities are important, but that groups, especially new groups might pose a particular challenge. Being given notice of change is of importance to this author, and for whatever reason, she is not actively involved in communication about activities that she is about to access, resulting in distress. Nevertheless, there are some people

involved with Sophie who understand her requirements and are able to assist.

Context and power



Figure 64: Context and power data from Sophie's narrative diary

This data speaks as facts about an activity. Difficulties such as researching are mentioned, but no information is given as to who is making decisions about the activity and number of choices provided. Detail about support is lacking, and depending on who is the author, the power over this detailing can be shifted between people or shared.

Diverse contexts are storied together with their distinct impacts on Sophie. Responsibility for miscommunication is not apportioned as there is a distancing between the author and the narrative itself. However, there is the implication that this somehow played an active role in the inclusion or exclusion of Sophie. Phrases such as 'the use of my strategy', 'the support' and 'I was able to cope' without accompanying detail, again lead me as audience to question the location of power within the context of this particular narrative.

Collage

The collage process which Sophie engaged in had four parts, namely production of a mind map, placing themes from her mind map under headings, the production of a draft collage and the final collage.

Mind map process

In the first stage, production of the mind map, I asked Sophie to think about themes relating to autism, which were important to her. However, as she appeared to find it difficult to begin writing on a large piece of paper, I suggested that we all think of possible themes, and I wrote down the word 'anxiety'. This seemed to have an enabling effect on Sophie as she began to write down her ideas (in red ink), and her mum and support worker joined in. Some of her responses were non-verbal, nodding or agreeing with comments, observations and thoughts expressed by her

mother, support worker or me. Sophie appeared quite comfortable exploring ideas creatively, and the mind map introduces feelings, people, activities and life events, and has a sense of Sophie's agency as we all wrote in different colours.

Image of mind map

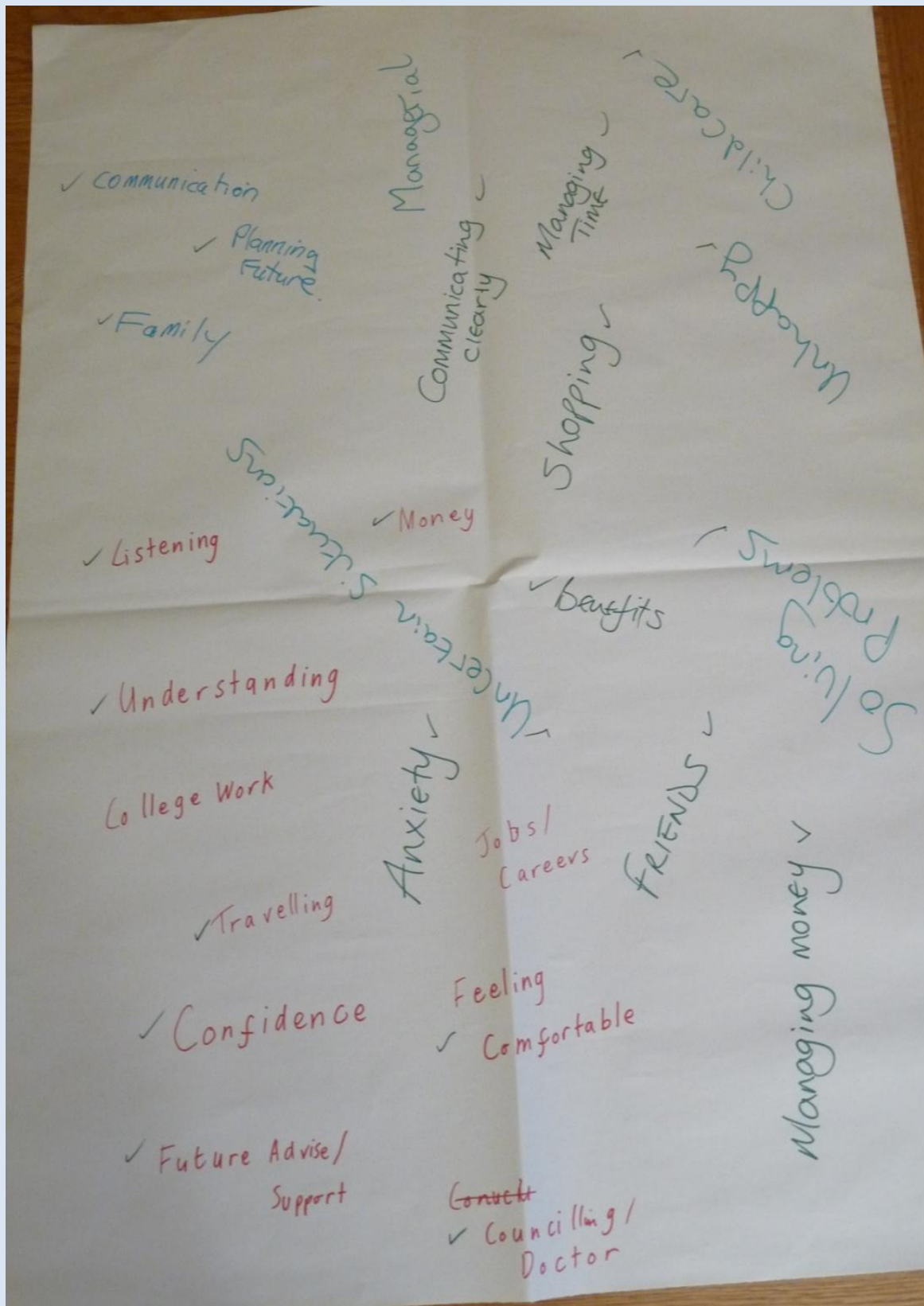


Figure 65: Sophie's mind map

Summary of Sophie's mind map data

Feelings and thoughts

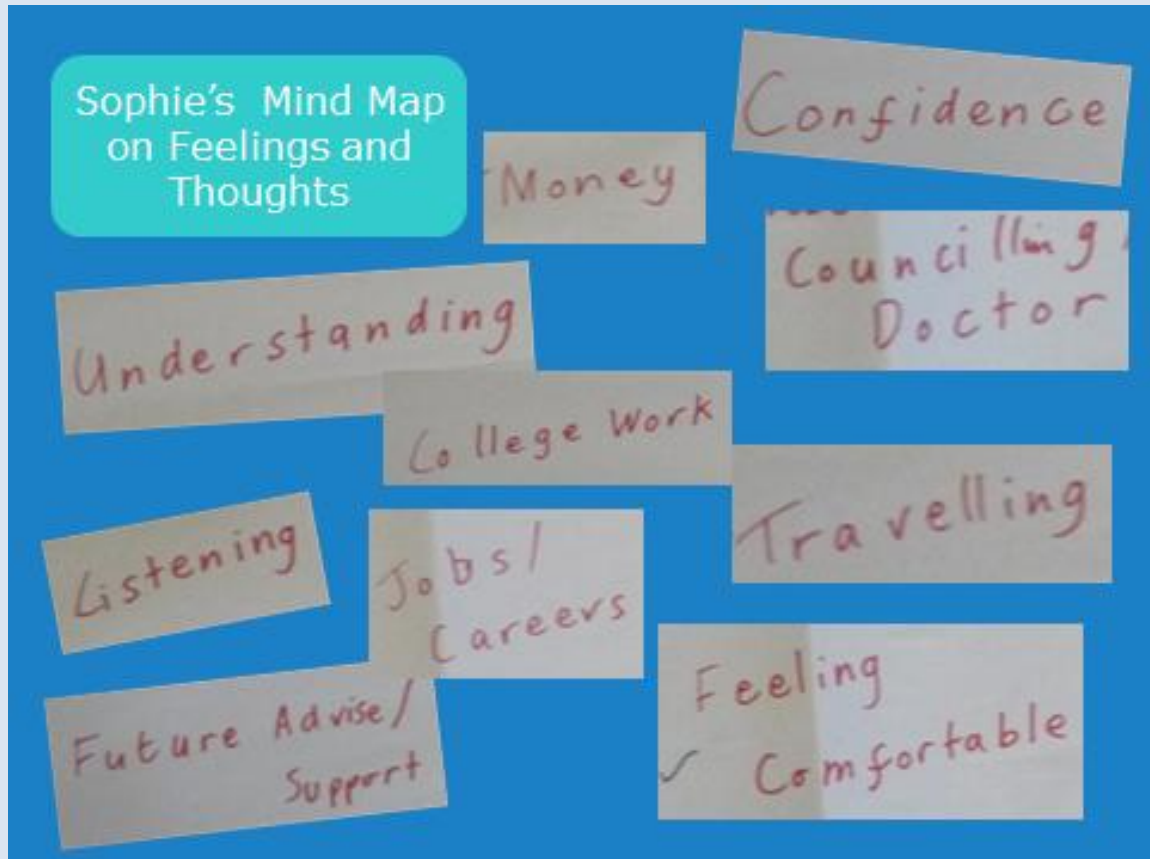


Figure 66: Sophie's mind map data on feelings and thoughts

In this part of the process, Sophie storied ten themes, not mentioning those already written by others present. Four were related specifically to feelings, and the remaining six concerned her thoughts or aspirations and support in attaining these or dealing with obstacles to these.

Identity and wellbeing

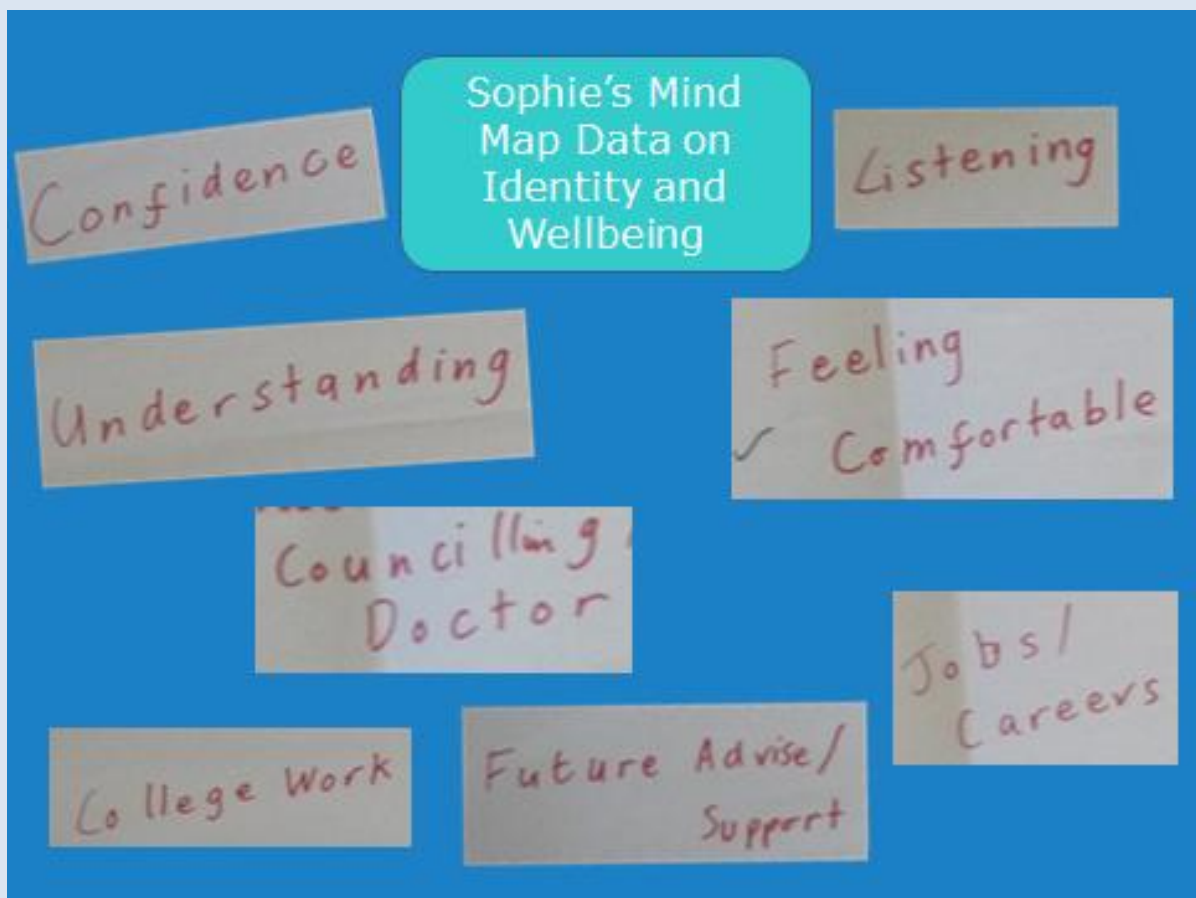


Figure 67: Sophie's mind map data on identity and wellbeing

Data provided by Sophie around her identity and wellbeing convey a fairly ordinary story about college work and needing advice and support at some future point regarding employment or a career. At the same time, Sophie informs her audience that there are issues around confidence, listening, understanding and feeling comfortable.

Context and power

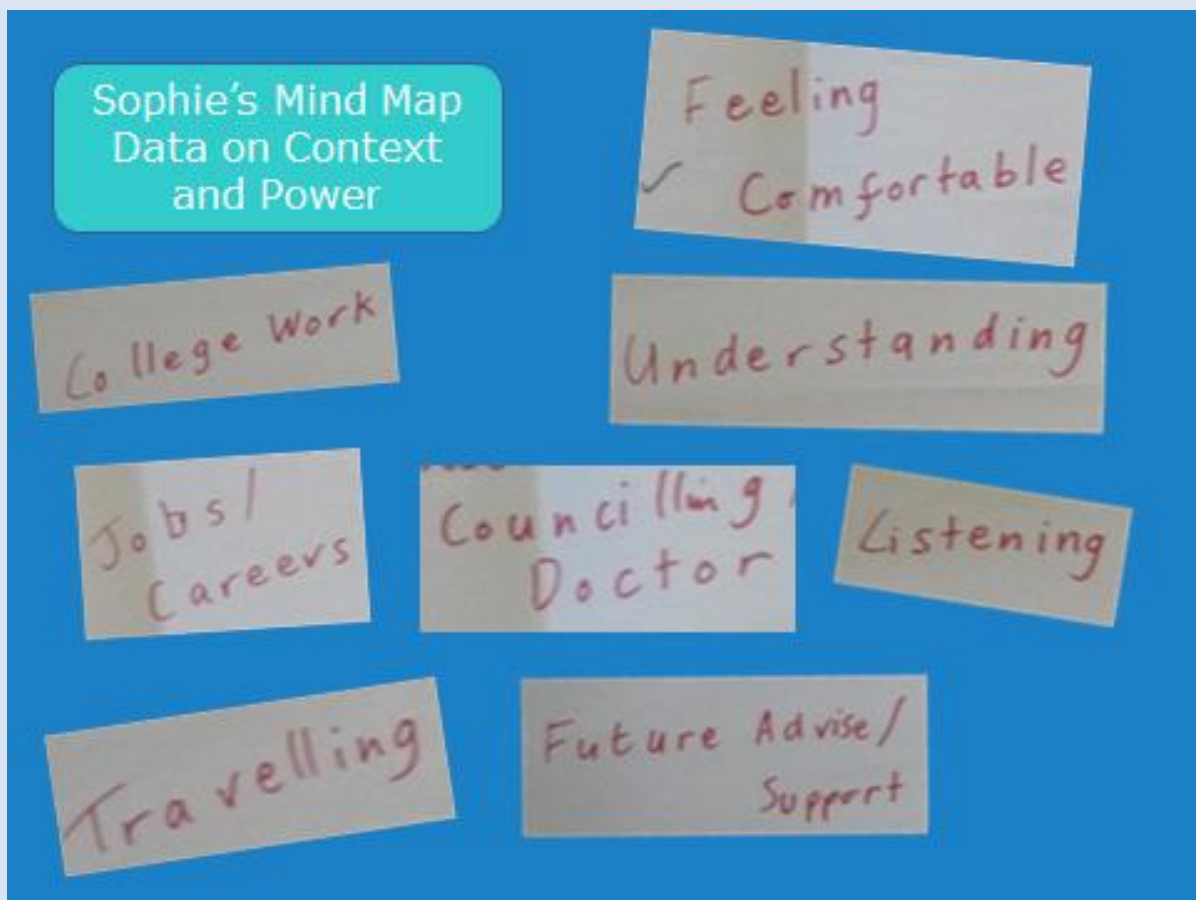


Figure 68: Sophie's mind map data on context and power

The data relating to issues of context and power in Sophie's mind map story three main contexts, namely college work, jobs/careers and travelling. The storying of power is contained in the data, which raises the question(s) as to who or what would make her feel comfortable, and who would have an understanding, listening role in her life and is able to provide advice. This is ascribed in the data to two people, a health practitioner and a doctor.

Process of placing mind map themes under headings

The second part of the process began in the second session and entailed Sophie choosing the headings under which to place her themes. Although there was potential for power to be imposed by others present, Sophie was decisive about the headings she chose, and her sense of agency was apparent. Interestingly, although she had written her themes in red, and given that I had not indicated whether to include or exclude themes introduced by her mother, support worker and myself, Sophie chose to include all themes written on the mind map against her headings. I had told her that she could place themes under as many headings as she liked, and she chose to do this, also adding the theme 'education', which was not in her original mind map. As we did not discuss this, I was not certain whether this was her own idea or whether it originated from her mother or support worker.

Image of Themes

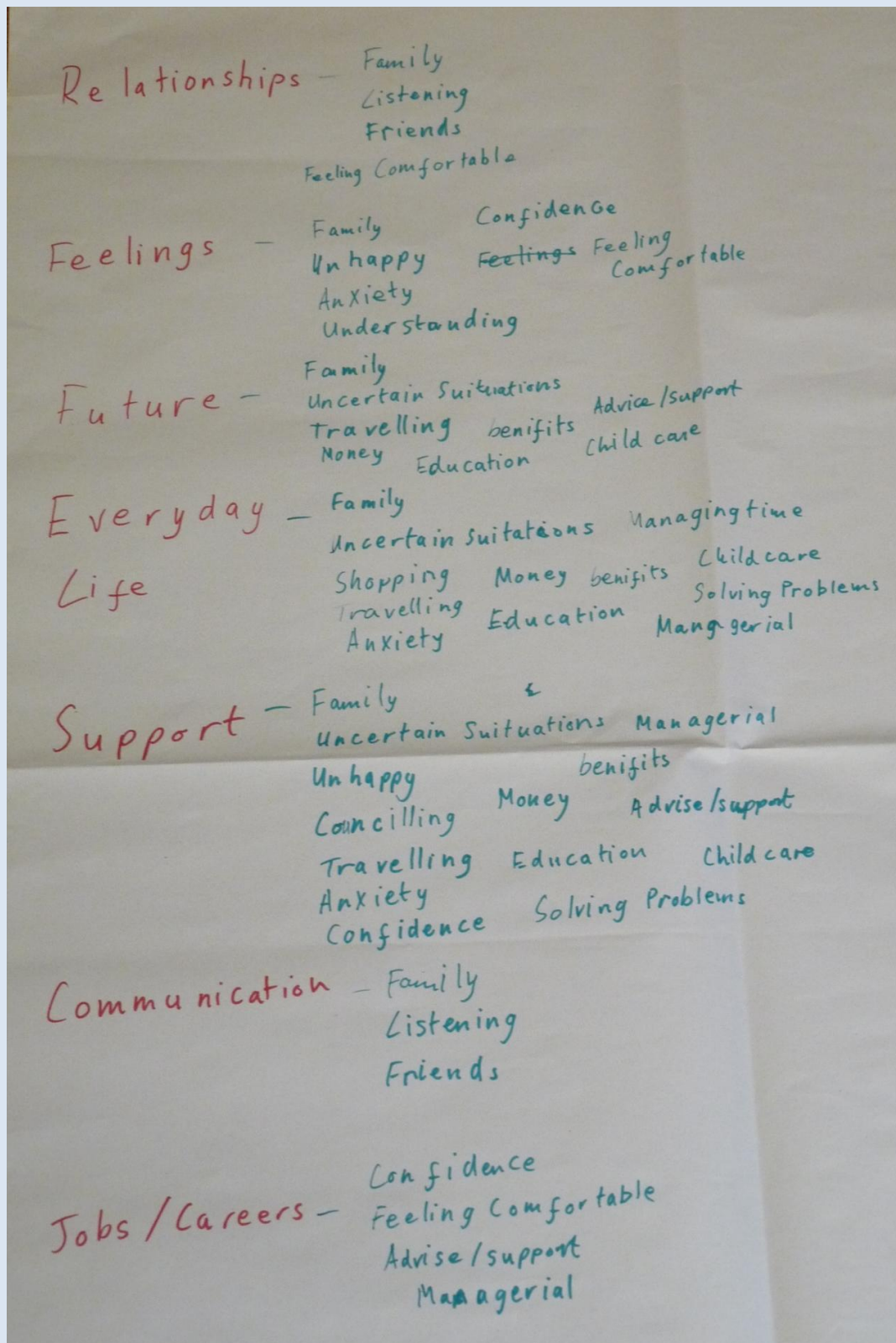


Figure 69: Sophie's Mind Map Under Themes

Summary of Sophie's headings data

Feelings and thoughts

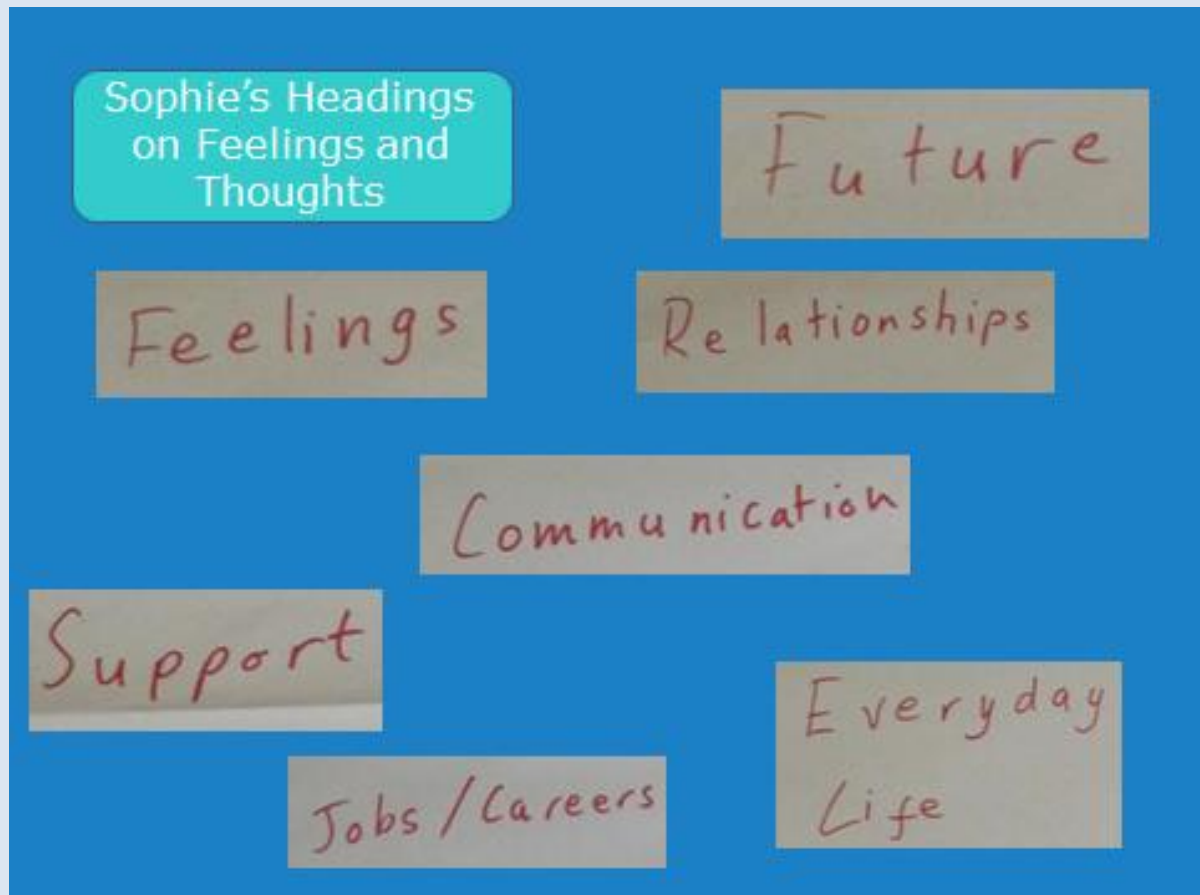


Figure 70: Sophie's headings data on feelings and thoughts

Sophie authored seven key headings for her narrative themes, and these indicated that the future, jobs and a career were important to her, with advice and support being a common theme echoed by the mention of uncertainty and confidence. Her mother had introduced the theme of 'planning [the] future on the mind map, and this became a main heading in the second part of the collage process. The themes relating to 'managerial' and 'childcare' stood out as being related to a more distant future, and although included at this stage, had been written by her

support worker. Also of importance were relationships and communication, which were very similar in terms of the themes attached to them.

Sophie's storying of everyday life is one reflecting themes introduced in the mind map primarily by others present, and the themes placed under feelings indicate a person in distress, mention feeling comfortable and name her immediate social group, her family. The heading about support has more themes attached to it than any other, and stories feelings, discomfort and present and future concerns.

Identity and wellbeing

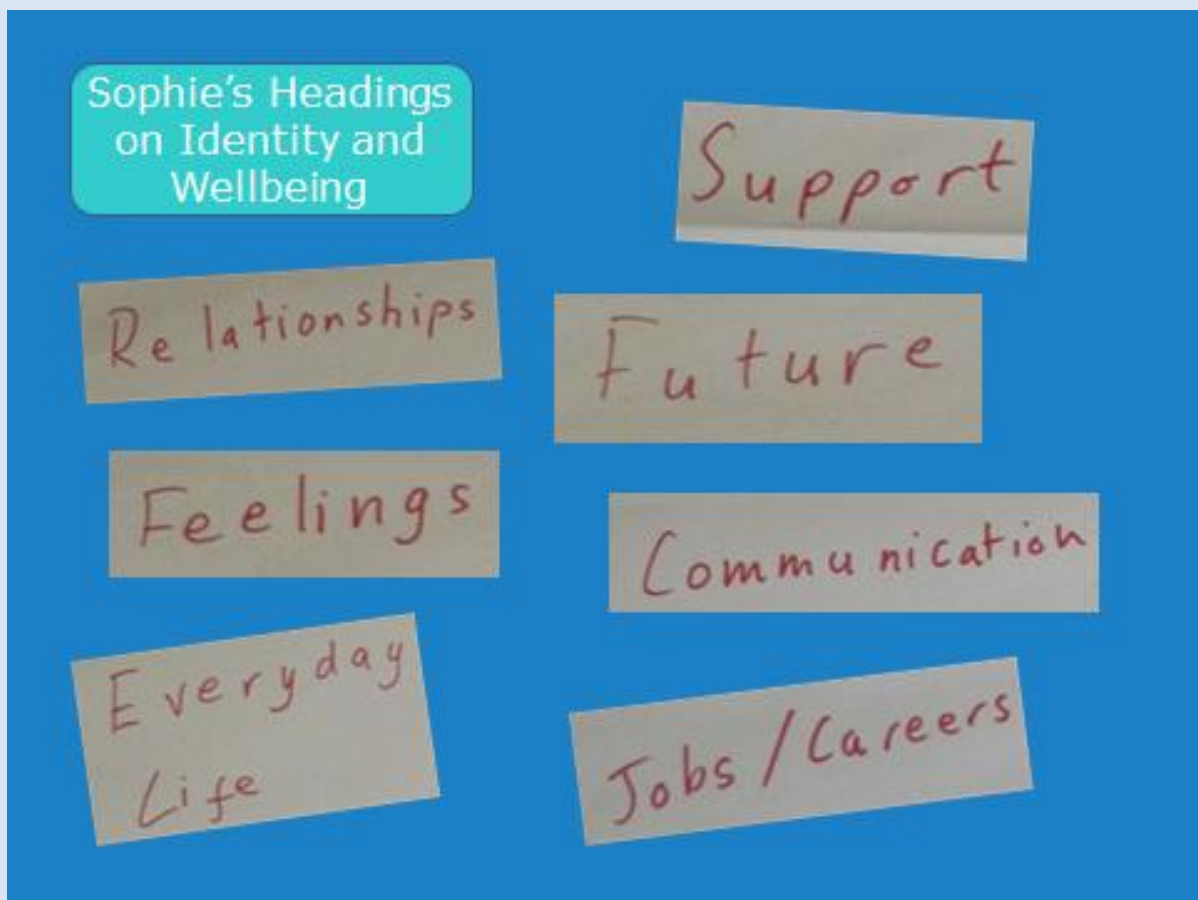


Figure 71: Sophie's headings data on identity and wellbeing

All of Sophie's headings included themes that spoke to identity and wellbeing. 'Feelings', followed by 'support' and 'everyday life' are the headings that indicate the greatest lack of wellbeing, and 'communication' and 'family' were the headings indicating a stronger sense of ease.

In terms of her identity, Sophie presents herself as someone requiring 'support' in 'everyday life' to handle several negative 'feelings'. The 'relationship' heading indicates that familiar people are perhaps more

understanding of Sophie's identity, and this may be supported by 'communication', which indicates that these people listen to her.

Context and power

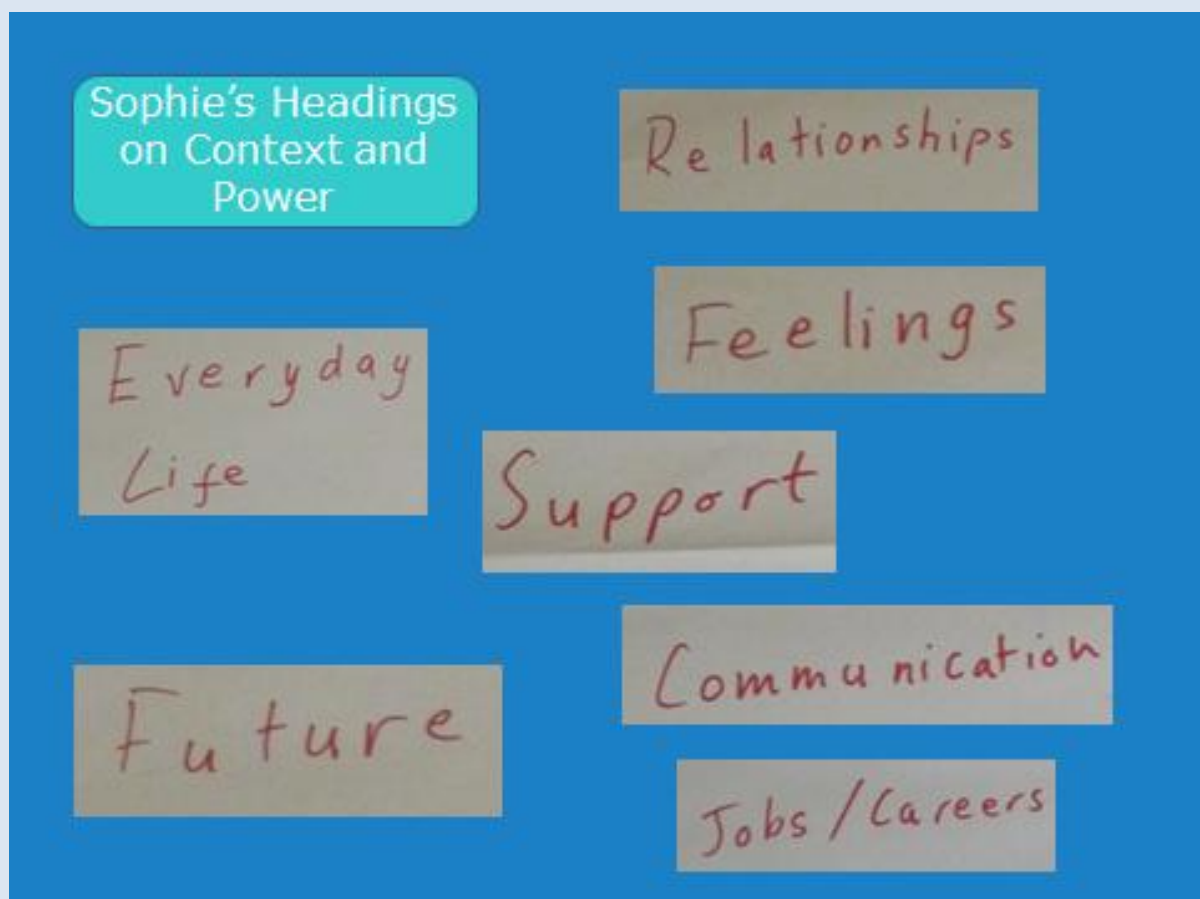


Figure 72: Sophie's headings data on context and power

In relation to my third research question, Sophie's headings all address context and power. However, depending on the context, power can be seen to manifest itself differently. For example, Sophie seems to story improved wellbeing with the themes she places under the headings 'relationships' and 'communication' as a result of being listened to. In the context of family and friends, power is shifted towards Sophie so that she

can express herself. In contrast, under 'jobs/careers', the themes suggest power over Sophie as advice and support would be required.

The heading 'feelings' introduces both negative and positive themes, and without the contextual detail of relationships, an audience would be left to question whether family played a positive or a negative role in her life. The remaining themes of 'everyday life' and 'support' story family, who have already been placed in the context of a supportive listening role under 'relationships'. In addition, there are several themes relating to unfamiliar territory and anxiety, and problem solving and counselling are raised as themes within this storyline. In relation to the 'future', Sophie uses themes which shift power over to others.

Draft collage process

Following the production of headings under which to place her themes, I introduced Sophie to different media – newspapers, magazines, felt tips and crayons. Although I thought that Sophie might be familiar with a collage process given that she studied art at college, I explained that in crafting a collage, she would be selecting images and looking at ways of linking them together to produce a different image that reflected the narrative she wished us to hear about autism. This part of the process is naturally quite messy, as the artist/author selects themes and images which resonate with them, and crafting a collage can result in several

intertwined storylines, which become quite confused. Certainly as an audience, I was unsure at this stage why some images had been selected or what they were linked to, although they appeared to be the authentic voice of each separate author, namely Sophie and her mother.

Image of draft collage



Figure 73: Sophie's draft collage

Summary of Sophie's draft collage data

Feelings and thoughts



Figure 74: Sophie's draft collage on feelings and thoughts

In comparison to the images selected by her mother, Sophie selects very few, but this reflects her processing of the story she wishes to tell in addition to finding the images to narrate her experiences. The images selected illustrate her feelings and thoughts at this stage and have a storyline of romance, love and a boyfriend. At the same time, there is a second story where she voices her thoughts and feelings around counselling, help and feeling comfortable in her skin. There is a sense of

uncertainty as to the agency of the helper in the image of 'how to help', and this is natural as part of a developing plot.

Identity and wellbeing



Figure 75: Sophie's draft collage on identity and wellbeing

Sophie's images as data around identity and wellbeing, speak to a narrative of someone who is either romantic or who craves romance and love. She also would either like, or has, a boyfriend, so that part of her identity is important to her. This suggests a soft, gentle and caring side to Sophie, but one that also welcomes or would welcome the same. There is

also a group identity mentioned, as in 'we need it', but with no detail as to the make-up of the group.

The plot around wellbeing suggests unease, where she needs to remind herself to love who she is. At this moment, I am not provided with data linking to this specific identity, only that she also stories counselling as part of this plot and something that is needed.

Context and power



Figure 76: Sophie's draft collage on context and power

The experiences plotted here tell of someone who requires support in the form of counselling. There is no story as to how this has come about, yet the 'love who you are' image is characteristic of a theme that might be addressed through a counselling session. This suggests that there is a certain context in which Sophie is possibly being told this and by a practitioner or family member, who she may consider to be in a more powerful position to her.

The phrase 'how to help' is interesting as it could mean that Sophie wants to tell others how to help her, and has a sense of her own agency. Alternatively, power could be located in the hands of non-autistic others who are able to help her in the manner that she needs.

Process of final collage

The draft collage session came to a natural end, so there was time for Sophie to reflect on the activity. Consequently, as my own feeling as an audience at this stage was that I had a sense of Sophie's voice on many themes, but no clear storyline, we flicked through magazines looking at adverts and musing over the purpose of posters. In this way, Sophie decided that they tended to simplify their image in order to clarify a message, and that this was what she wished to do between this session and the next. Therefore, whilst all the images selected in the draft collage might have been relevant to her wider narrative, we deliberated over the

need for clarity in order to assist the audience to understand her key narrative(s). The purpose of this approach was to help Sophie locate her voice at the fore in storying her experiences.

I was interested in how Sophie constructed her final collage. Whilst some of the phrases were selected as a complete phrase or word from the magazines used, others were constructed from letters. For me, I felt this highlighted Sophie's creative skills and interest, and the crafting of individual words placed an emphasis on her alteration of the message being conveyed. This was helped with her use of crayon to draw arrows and a plus sign, to which as an audience I then almost subconsciously attached my own phrases in order to arrive at my own interpretation. The word 'confidence' was constructed so that in addition to comprising separate letters, these letters gave a 'broken' display as represented by different levels. This is in contrast to the word 'change', which had a smoother and less disjointed impact on me.

Image of final collage



Figure 77: Sophie's finished collage

Having reflected for a week on her draft collage and our discussion, Sophie produced her final collage on her own, and with her mother, her support worker and me present. Sophie told me that on the left-hand side of the collage she had storied the negative themes she wished to highlight concerning challenges in relation to autism, and on the right-hand side, were solutions to these.

This final collage is entirely different from the draft, and this is often very characteristic of a collage process. Sophie has made use of her artistic skills and explored materials in the construction of themes relating to a very clear central message.

Summary of Sophie's collage data

Feelings and thoughts



Figure 78: Sophie's final collage data on feelings and thoughts

The data presented shows how Sophie is voicing her thoughts and feelings. She starts at the top of the final collage with an image of broken confidence and links it to a solution stating that she needs to love who she is in order to be confident. As an individual, she worries a lot and requires comfort. She wants change (and this is a smoother image than the one about 'confidence') for a good future, and her solution to problems are best friends, who provide her with instant relief.

Sophie has made use of different materials, used phrases and distorted and reconstructed images to story her experiences, and her creativity is apparent in the way that she is linking ideas. The use of different media have enabled her to process a narrative that was not a prominent part of the draft collage, but which has been a strand in all parts of the process of authoring her experiences.

Identity and wellbeing



Figure 79: Sophie's final collage data on identity and wellbeing

Sophie selected images that pursue a storyline of an unconfident person who needs to be reminded to love herself. It is unclear which part of her

identity this relates to as the data tells us that she has more than one identity, one of which is Asperger syndrome.

The linking of ideas by Sophie is done both in terms of identity and wellbeing. An audience can understand that she is not satisfied with things as they are and wants change for the better, and the data suggests that she is someone who has problems and worries as a result. As such the storyline around wellbeing is more suggestive of mental distress.

Context and power



Figure 80: Sophie's final collage data on context and power

The contexts are not precisely storied in Sophie's data. As an audience I can understand that certainly some are unpleasant or problematic and she requires comfort from others, and this may shift the location of power. In addition, in some context(s) Sophie has been informed that she has Asperger syndrome, and it is uncertain whether this is what is causing her to worry or experience problems. However, the collage remit was to story her experiences of autism, so it would be reasonable to reflect on this possibility. Nevertheless, there is a storyline in the images that suggests that Sophie might be being told, or feels that she has, more than one identity as she also stories this. However, apart from the sexual orientation image around having a boyfriend, introduced in the draft collage, there is no mention as to what these other identities might be.

Whilst the collective 'we' image relating to support does not detail the group membership, power to provide support is certainly located outside Sophie and could relate to any of her identities, or to her family.

Summary of Sophie's mum's narrative data

Sophie's mum storied three themes in the mind map, namely communication, family and planning [the] future. The images Sophie's mother chose were generally those placed on the left hand side and the bottom right of the draft collage, whilst Sophie placed her images in the top right corner and randomly across the middle. This draft gave me

The narrative produced by Sophie's mum contains images which provide a sense of overwhelming past and present problems. The data also speaks to plans for a different future, where issues such as education, work and moving house play a part in reaching a more relaxing destination. The need for change is a central feature of this story.

Identity and wellbeing



Figure 82: Sophie's Mum's narrative about identity and wellbeing

Images provided by this data speak of someone who is drowning in problems from which they need to be freed and medication is the source

of comfort and instant relief storied. The data provide an image of someone who feels overwhelmed.

Context and power



Figure 83: Sophie's Mum's narrative about context and power

Sophie and her mother fell easily into working together on her draft collage, silently negotiating the spaces for their images. There was ongoing discourse around support and autism throughout, with Sophie listening and nodding, and her mother mentioned that there were other disabled immediate family members. This began to establish a context of outsider power over a situation, and I personally felt a little

uncomfortable with this. Although I considered asking Sophie's mother if she would like to pursue her own narrative separately, I decided not to break the seemingly natural and unspoken rapport between them. However, as mentioned, she had chosen an area of the card on which to place her themes, and they did reveal a story about the pressures imposed by society of fitting into a normative agenda.

Researcher Analysis

Feelings and thoughts

Interpretation 1:



Figure 84: Sophie's use of pre-constructed images

Sophie uses the medium of collage to process her thoughts and feelings in relation to poor confidence, and she relates this to not loving or accepting who she is. Matching these messages with the narrative text, her identity as someone who worries seems to explain further the textual messages of 'struggling to cope with last minute changes' or needing someone around who 'understands my difficulties'. Sophie's selection of these images was in the context of her final message written in crayon, namely 'I have Asperger Syndrome'. The images suggest to me that Sophie is detached from an autistic community actively involved in challenging society's perceptions of autism and related barriers to inclusion. In addition, as audience to her collage, my impression is that Sophie is encased in an identity shell (Bornstein, 2013), as the prominent messages are of someone with difficulties, who needs understanding, and who struggles. For me, these images expose the constraining limitations of power, which I feel characterised her narrative diary. As a contrast, this offered a narrative of someone who was achieving set goals with support, and this disparity leads me to consider the location of power within the narrative text, as it appears to contain an undercurrent of autistic subordination.

Interpretation 2:

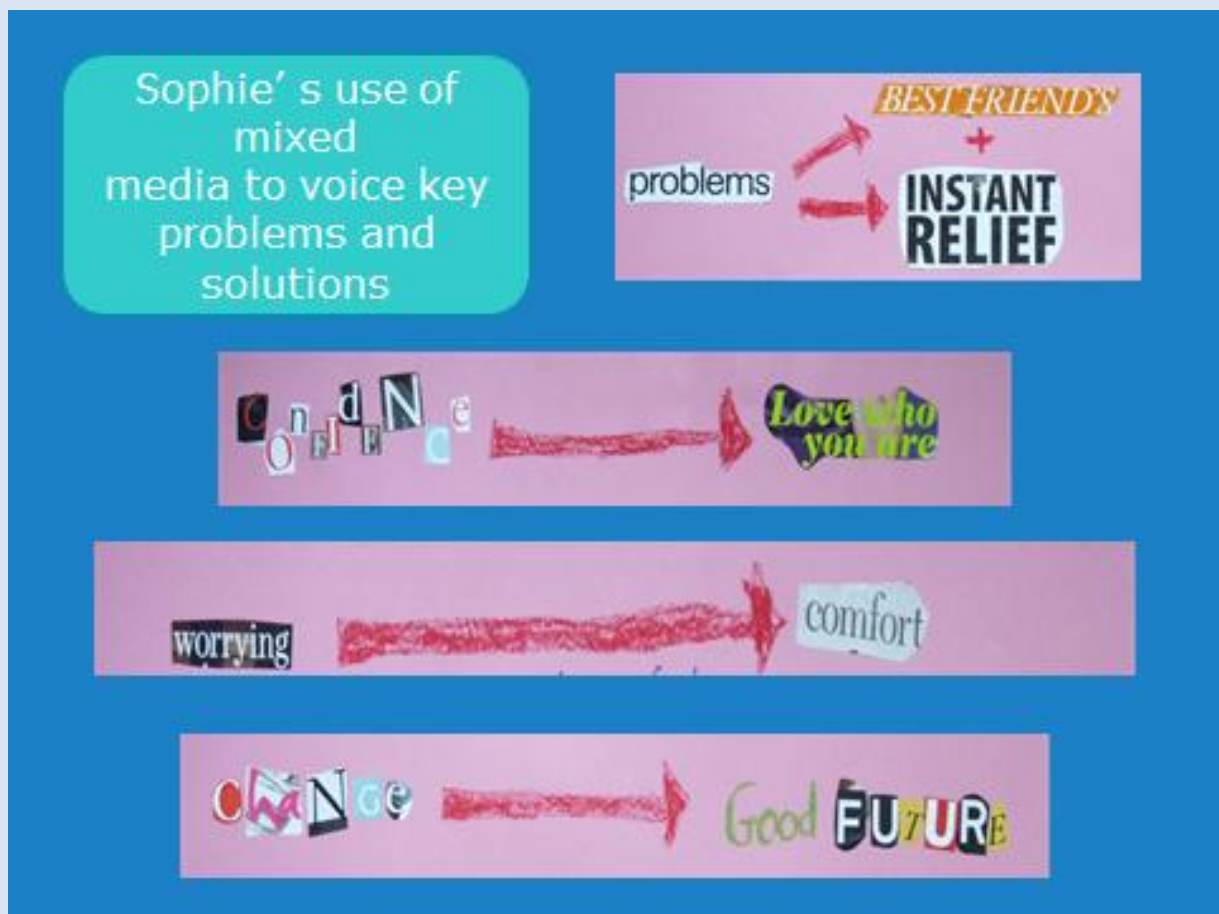


Figure 85: Identification of key concerns and solutions

With an interest in art, Sophie was able to exploit different media within the collage process to bring her voice to the fore regarding a prominent theme in her narrative, anxiety. In so doing, she deconstructed and reconstructed images, freely linking some using crayon. As such, she was able to present motivational messages to herself, inform me about solutions that worked for her, and craft images regarding areas she wished to build - 'confidence', 'change' and a 'good future'.

My sense was that Sophie had needed some support in voicing her key narrative message(s) clearly. However, I was beginning to see how the distinct processes working with mixed media enabled her to work in both a restricted and a more liberated way depending on the context.

Sophie had discarded most of the images introduced by her mother and also those which she had previously selected for the draft collage. My reaction to this was that these discarded images reflected a social world comprising pressures to conform to social norms, and that these were not her more immediate concern. In addition, they reflected wellbeing as demonstrated in the differences between the communication of quality of life issues relayed by autistics and non-autistics, and these may have contributed to Sophie's anxiety.

Identity and wellbeing

Interpretation 1:



Figure 86: Asperger syndrome and its impact

In this narrative, I have selected images that show Sophie's storied identity as someone who 'has Asperger syndrome'. This use of person first language suggested to me that Sophie considered autism to be an appendage (Sinclair, 2007), and one which, when linked with other components of her narrative, led me to believe that it was an unwelcome part of her as it brought challenges. Furthermore, her acknowledgment that she has multiple identities suggested to me that she perhaps felt

more at ease with these, or that they were waiting discovery and exploration.

Whilst her support worker is the person referred to in the text as understanding Sophie's difficulties, her list shows that it is family and friends who provide her with comfort. Perhaps she included her support worker among these.

Interpretation 2:



Figure 87: Impact of support on Sophie

This new story focuses on support and confidence. The fact that others are interlaced within the narrative, does not necessarily offer less credence; however, as Sophie's collage process and image primarily voice anxiety and mental distress, as an audience I wish to understand the balance between these two stories. This is critical in order to make sense of Sophie's current real life experiences and points to further possible avenues to explore with her regarding appropriate and relevant support.

The final image produced in the collage had a central message, which was more focused on issues of confidence and gave a wider array of causal explanations and solutions. This contrasts with the main images from the text. For this reason, this interpretation presented demonstrates the need to search images and look to contextual clues in determining whether the presence of a familiar person is enabling or disabling in the storying of personal experiences.

Context and power

Interpretation 1:



Figure 88: Location of voice

My interpretation of the above images is that although Sophie herself actively constructed an image of 'change', the other components demonstrate a distancing of her voice and possibly a negotiated narrative. The focus in the text, as opposed to that of the collage, has shifted to one of a 'strategy' and 'support' provided by a named worker to enable Sophie 'to cope'. This is an important finding as regards my third research question, as it demonstrates how, where and why the voice of an autistic individual may be lost, given less credence or skewed. Consequently, the

real impact of context and power on the shape of a narrative then becomes apparent.

Alternatively, the above images may be seen as offering an opening to engage with Sophie and explore details around her support. In addition, I am interested to know whether anyone suggested that Sophie story a lack of support as the language suggests a lack of agency, and points to a possible power over Sophie to include this component of the storyline. Consequently, whilst it has an important role in illustrating how support has been enabling, I wonder whether this is the main story that Sophie herself wishes me to hear.

In my literature review, I discussed how an individual's sense of agency directly impacts on their wellbeing (NEF, 2012; Tew, 2015), and this textual image reveals the support worker's potential power over the process. Whilst the storying of support provided seems to suggest that her support worker has an enabling role, the frequent naming of her sits uneasily with me and leads me to question the power dynamic further.

These images provoke a sense of frustration in me as an audience, as I feel that Sophie's voice is becoming lost in a narrative that may not be entirely hers. My research questions enabled me to structure my own thoughts and to consider whether mixed media enable Sophie's voice to

come to the fore regarding her feelings and thoughts. In the text, I found little evidence of this, but it did emerge in her collage.

Interpretation 2:



Figure 89: The easier story to tell

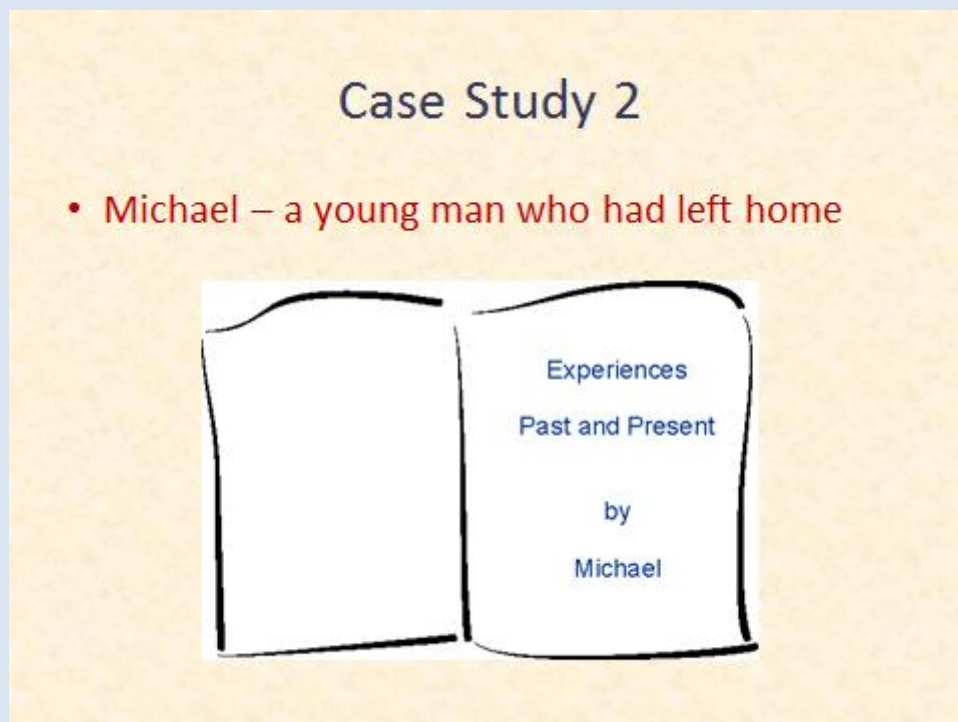
Several questions arose when I read specific aspects of the narrative text as regarding agency and the authenticity of Sophie's voice. My first question concerned whether Sophie had chosen to do this climbing activity, or whether there was an element of Sophie's identity/service provision that was more about an eager parent, and maybe even her support worker, who wanted her to achieve.

Another perspective is whether the story the images tell is the easier one for Sophie to narrate given that the sub-text stories anxiety, struggle and distress. Certainly the contribution this narrative makes cannot be negated, but it does indicate that its priority might be different in Sophie's wider storying of her experiences.

As an audience, I consider power to be embedded in this narrative image, since if, as Sophie says, she finds researching activities difficult, I am then led to question how she manages to assess the suitability of one such as climbing. Maybe explaining this step by step process is perhaps less challenging, but is left unanswered, and as the process of researching is not explored this may demonstrate a missed opportunity in terms of assisting Sophie to develop research skills.

Having presented and analysed the processes and images from my first case study with Sophie, I now present those corresponding to my second case study.

Narrative case study 2: Michael



Context

My second case study concerns Michael. Michael had been involved in a meeting to discuss the requirements of autistic adults in a specific geographical region, and this led to the establishment of a support service. Although living independently, daily contact from his parents was necessary to provide support, and additional links with services were required as they were 'aging parents'. Consequently, Michael was able to obtain support on a 1:1 basis to help him build strategies for independent living. In addition, he was attending a support group for autistic adults and their family members.

Michael's narrative was selected for my study as an example of opinions from the perspective of an autistic individual who has been involved in

informing a service. Michael had completed a questionnaire to evaluate the support service he was involved in, and from this, he subsequently chose to story his experiences using narrative text, including graffiti-style lettering, a picture, a diagram, and a collage.

Narrative diary

Process

Michael had been informed by staff that the support service was to be evaluated, and prior to my contact with him had been asked by his support worker if he would like to write about his experiences in relation to autism and the support he now received. Michael may have felt placed in a position where the support service/support worker had imposed power over him in terms of requesting a narrative. The support was being evaluated, and his feedback was important. Nevertheless, for Michael the balance of information exchange also appears to have been of equal importance, with him asking the support worker to share information on supporting a man with Asperger's syndrome. Michael produced his narrative text individually.

Image p1

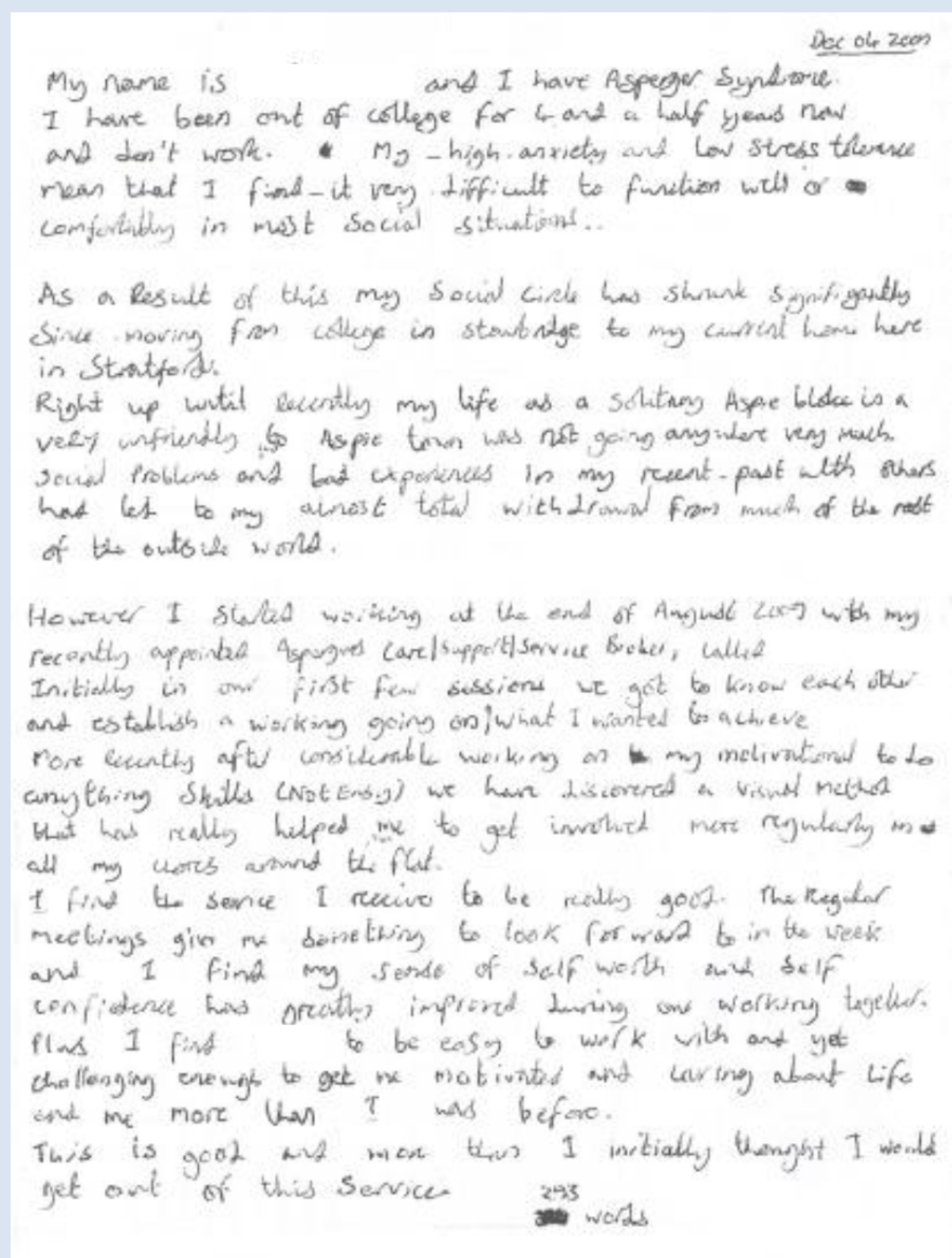


Figure 89: Michael's narrative diary p1

Michael's textual image begins with a statement about the identity he is about to story, and one which uses medical model terminology (Sinclair, 2007). I am then introduced to a summary of his situation regarding education, employment and the impact of social situations.

The second paragraph describes a continually reducing social circle as a direct result of living in what Michael stories as a town which is not accepting of Aspies. This is also linked to past bad experiences.

In the third paragraph, a new storyline is introduced as Michael has an appointed support worker, and he speaks of a format involving introductions, establishing goals and a visual tool to encourage and develop motivation and organisational skills.

In the final paragraph on this page, Michael voices his opinion of the support service and the worker involved, and he gives details as to how it has impacted on him. In addition, he compares this impact with his previous expectations of the service.

Michael's narrative is very reflective, allowing me to understand his ability to develop some very sophisticated coping strategies with varying degrees of success. The text allows him to introduce and explore storylines briefly, giving sufficient detail for me to understand historical and present stressors, such as not being in education or employment, withdrawal from social situations, anxiety and an inability to tolerate this stress, to explain how he has arrived at his current life situation.

Summary of Michael's narrative diary data p1

Feelings and thoughts

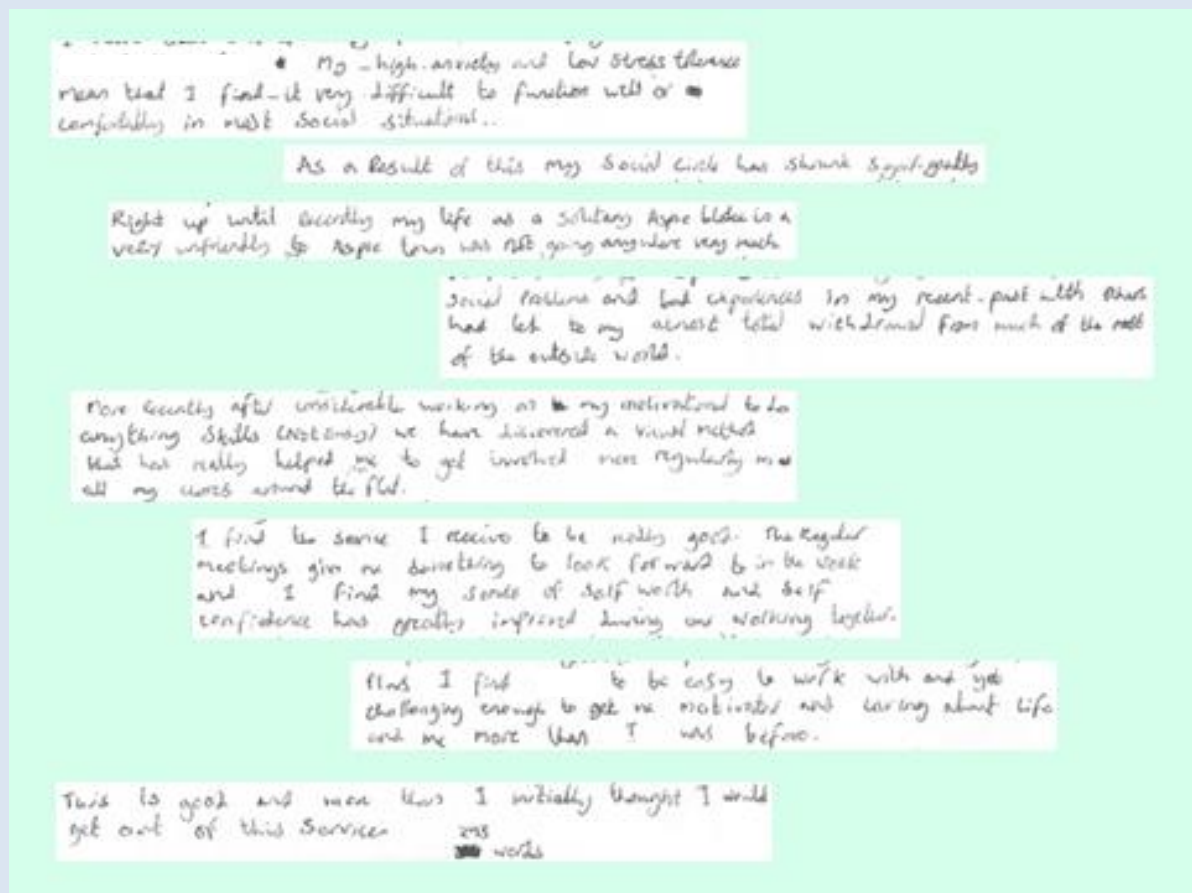


Figure 90: Michael's feelings and thoughts voiced in his narrative diary p1

After a statement about his current situation, Michael uses this narrative tool to help him reflect on past and present situations, telling me about the cause and effect of each. As the narrative plot about his support worker is introduced, the data reveals a change for the better in Michael's life, and a visual tool, which he developed with his support worker, has enabled him to become motivated. The text tells me that being able to relate to his support worker was important, and that he also needed someone who challenged him enough to care about his life again. This

was something the support worker was able to do, and as a result, it tested his expectations of the service in a positive way.

Identity and wellbeing

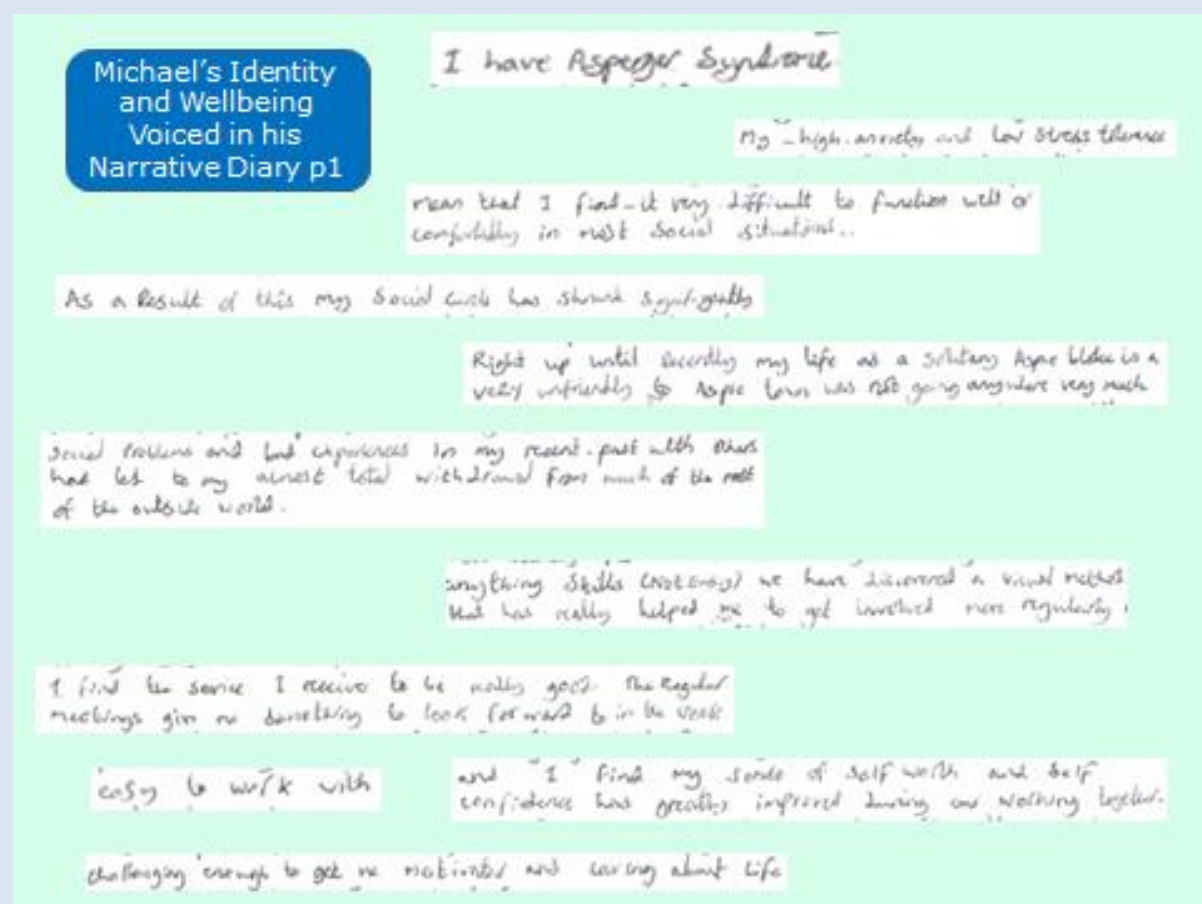


Figure 91: Michael's identity and wellbeing voiced in his narrative diary p1

In Michael's first sentence, he introduces himself as someone with Asperger syndrome, and also uses the word 'Aspie' to describe himself, which shows an identity with the autistic community. The data suggests that being out of college and work for this length of time will only have contributed to any pre-existing anxiety and stress. At this stage, Michael does not describe the feelings that he must have experienced at not being

able to continue his education or engage in work. However, as he gradually stories his current situation, he draws me into the contextual detail necessary to understand this aspect. The impact of this is described in terms of low hedonic and eudaemonic wellbeing due to his isolation from social settings. In addition, Michael sees his identity as separate from that of non-autistic others. His wellbeing is also storied as distress in terms of bad past experiences including [unidentified] social problems.

Michael's mental distress is referred to in terms of social withdrawal, a lack of motivation, low self-worth and confidence. His involvement with an easy going support worker, who involved him in providing solutions to his problems and also challenged him, had a rapid and positive impact on his wellbeing.

Context and power

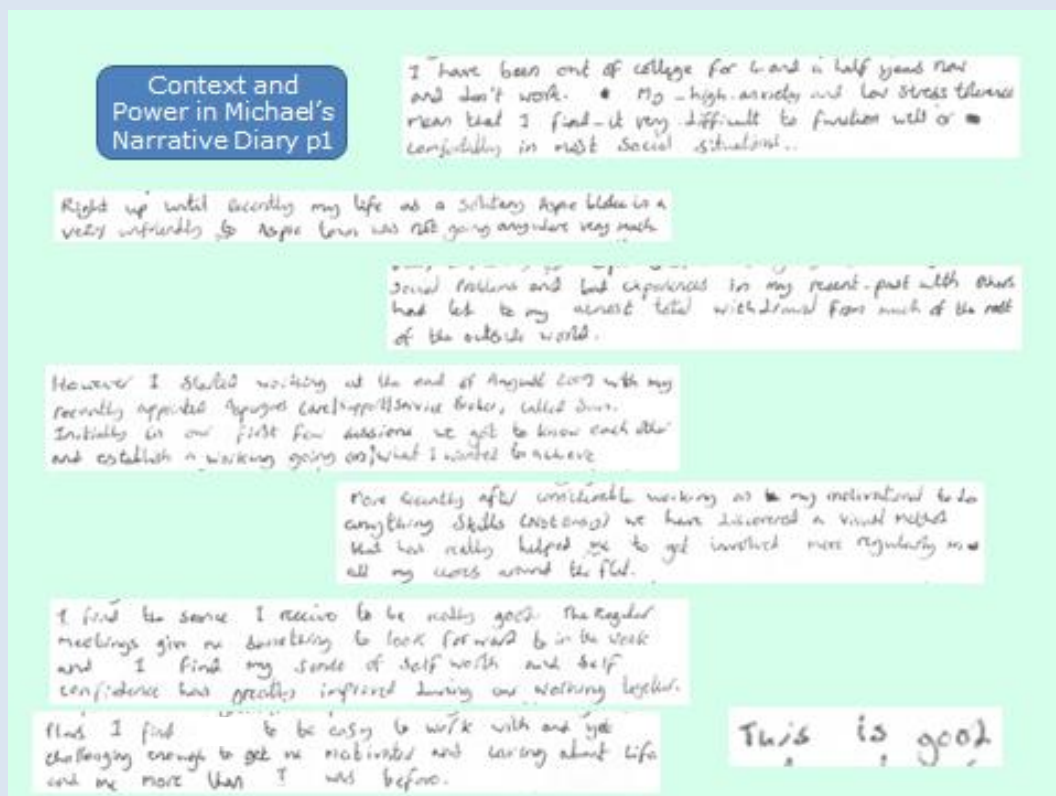


Figure 92: Context and power voiced in Michael's narrative diary p1

The directness of Michael's narrative opening, and the use of 'I' suggest an authenticity of voice. He then uses this medium to introduce his audience to a named support worker, and the narrative continues around their work together.

Interesting to me is that Michael managed to negotiate a sense of space as the format of his presentation was his own choice, and he included a word count. This latter was because he had insisted that if he was being asked to story his experiences as an autistic individual, then the support worker also write a narrative of a stated word length (not given to the researcher) about their experiences of supporting an autistic individual.

This gave me the impression that Michael had not wished to be 'under the gaze' of non-autistic others (Moon, 2014c). Michael's narrative was given to me by Social Care staff. I took from this that Michael, as an individual being supported, required an information exchange with support staff in order to shift the dynamic from 'power over' him to one of 'negotiated power'. I wondered whether this would be an illustration of a 'convincing life coping strategy', as mentioned on the second page of his narrative text, as it would seem to me to be an effective way of managing any accompanying anxiety that this task might create.

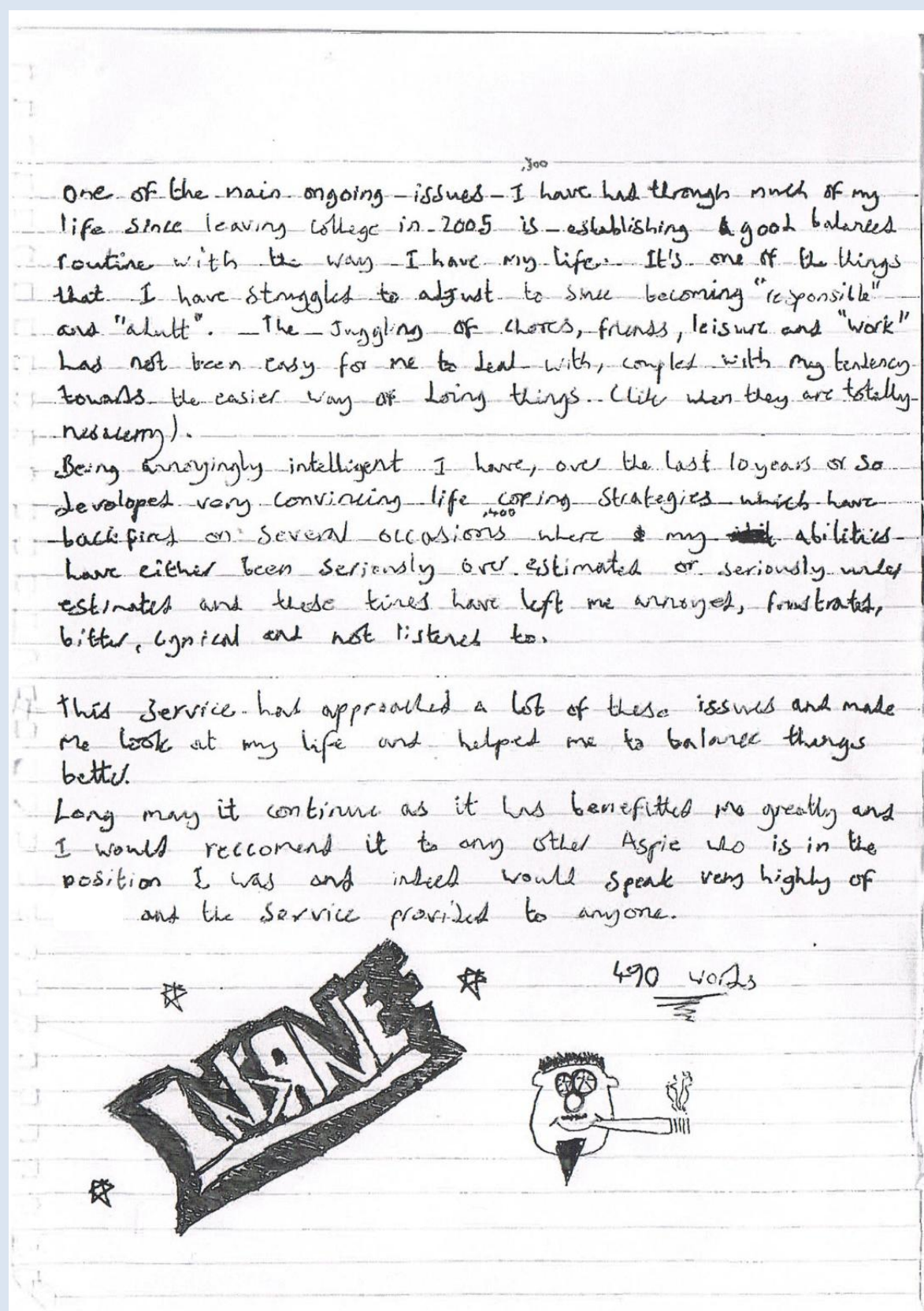


Figure 93: Michael's narrative diary p2

Summary of Michael's narrative diary data p2

Feelings and thoughts

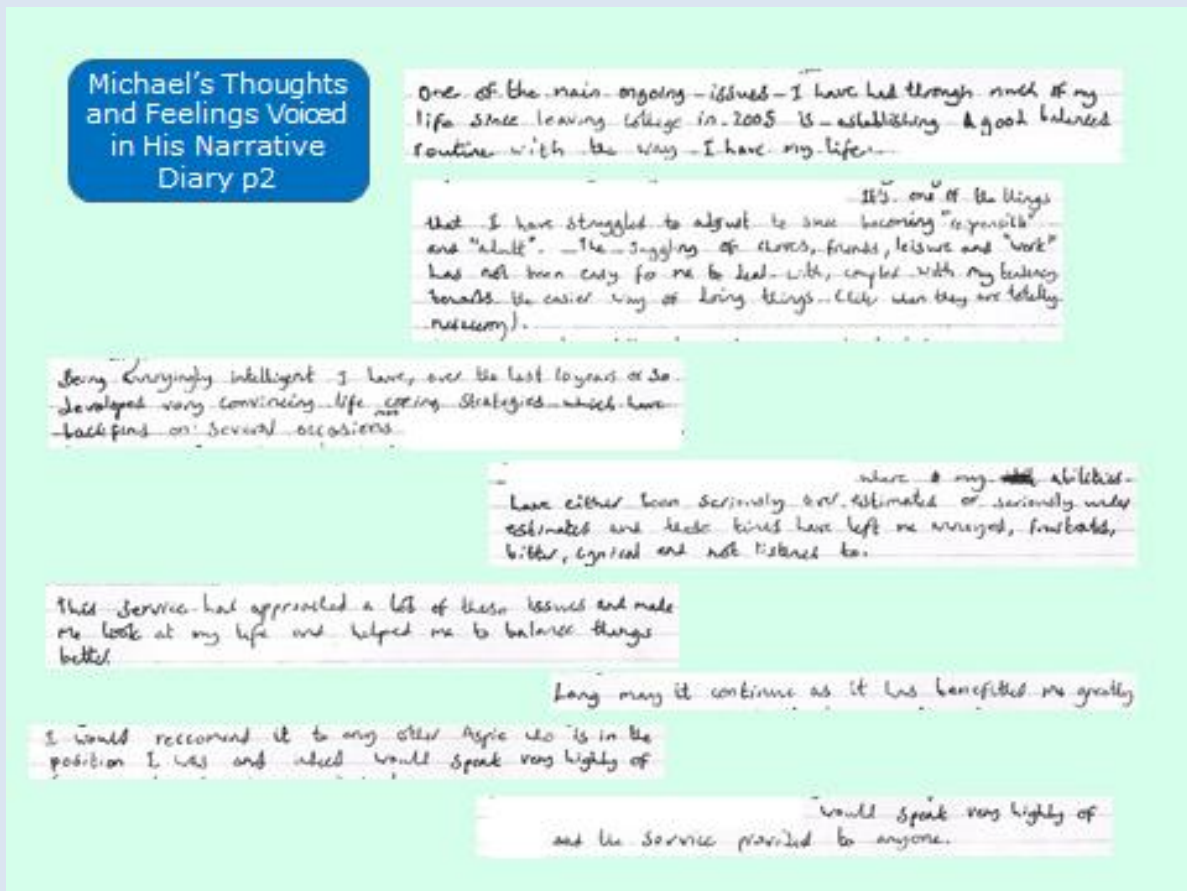


Figure 94: Michael's voiced feelings and thoughts in his narrative diary p2

The initial narrative on p2 introduces Michael's struggle to establish a balance in his life, and he links this to being a 'responsible' 'adult', which he puts in quotes. The result of the above has been that Michael has been able to think through the need to establish coping strategies and implement them, but these have been unsuccessful. The data speaks to a negative impact on Michael's wellbeing due to others misunderstanding his skills and abilities, and this has led him to question the merits of coping strategies, engaging with others, or both. Clues to this also occur

earlier in his narrative, where he stated that his anxiety may lead to withdrawal and a failure to engage.

The introduction of a support service has been beneficial to Michael, and initially when talking about the contribution of this, Michael's language creates a sense of space, namely 'this service has approached'. However, a sense of his authentic voice and ownership takes over as he states what he would like to happen to it and recommends both the service and his named support worker to other Aspies. This is a key message for autistic people and service providers alike, and this medium helped Michael express his views.

The data on this page walks us through from a starting point of considerable struggle and solitary existence, to a point where there is a sense of purpose in Michael's life.

Identity and wellbeing

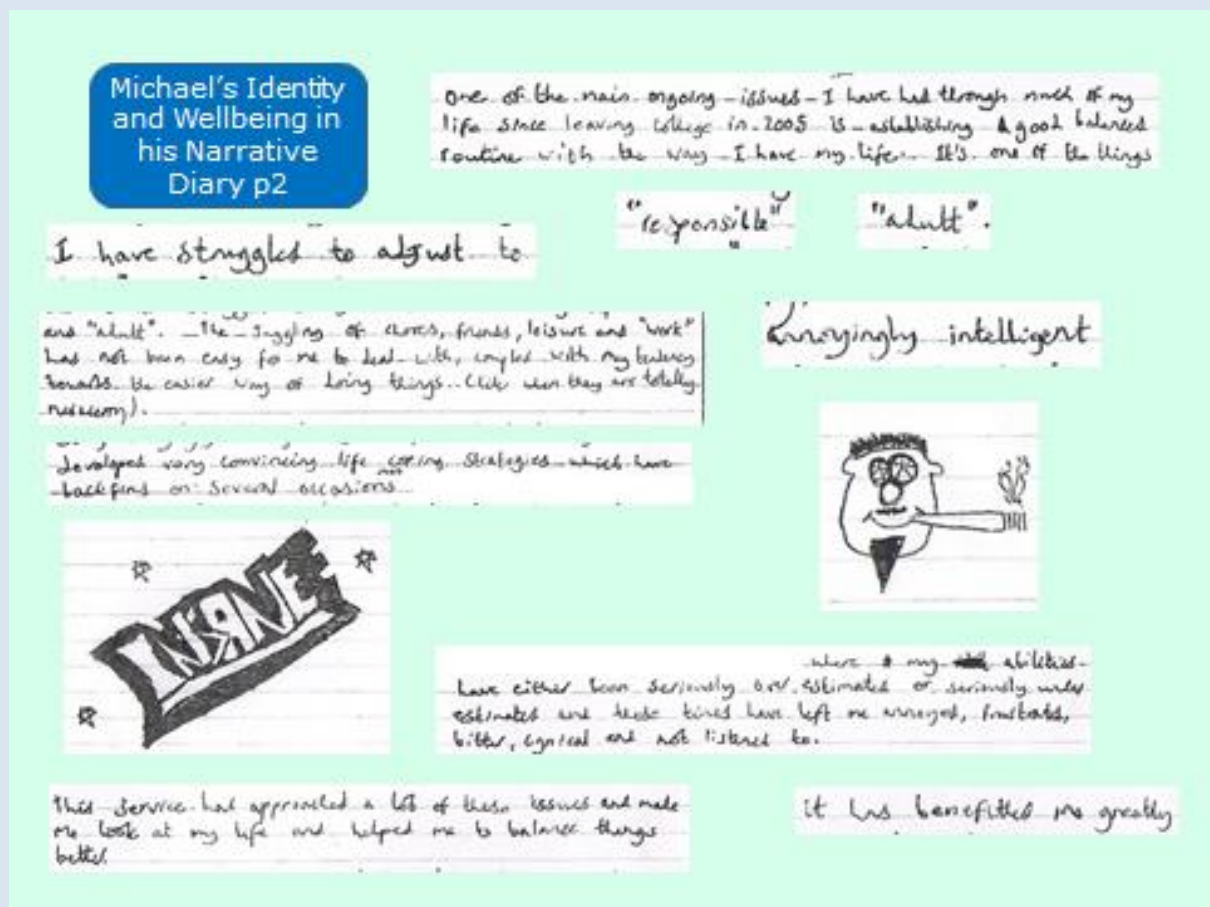


Figure 95: Michael's identity and wellbeing in his narrative diary p2

Michael stories his wellbeing and identity in terms of being unable to establish a routine in life in terms of a 'struggle to adjust' to the expectations of being both 'responsible' and an 'adult'. This text informs us that this expectation would seem to clash with his natural way of being, which is perhaps more relaxed.

Michael stories himself as someone who can think about things that require a strategy. Nevertheless, there is a disconnection between what Michael perceives to be a good strategy and what actually works, as non-

autistic others misunderstand him. His mental distress comes to the fore in this moment in the form of frustration at being disenfranchised. The implication in Michael's text is that the service has been autism friendly, as a lack of this is what has resulted in his previous disengagement and withdrawal, and it has had a positive effect on his wellbeing.

There are identity descriptions of Michael being 'annoyingly intelligent' and 'insane', yet it is unclear as to whether Michael sees himself as these or whether these are imposed identities. In addition, Michael's support worker informed me that the smiling face was a picture of Michael smoking. Interestingly, the eyes have been drawn almost like pie-charts, which are taken up as images on the following page in terms of organising his life.

Context and power

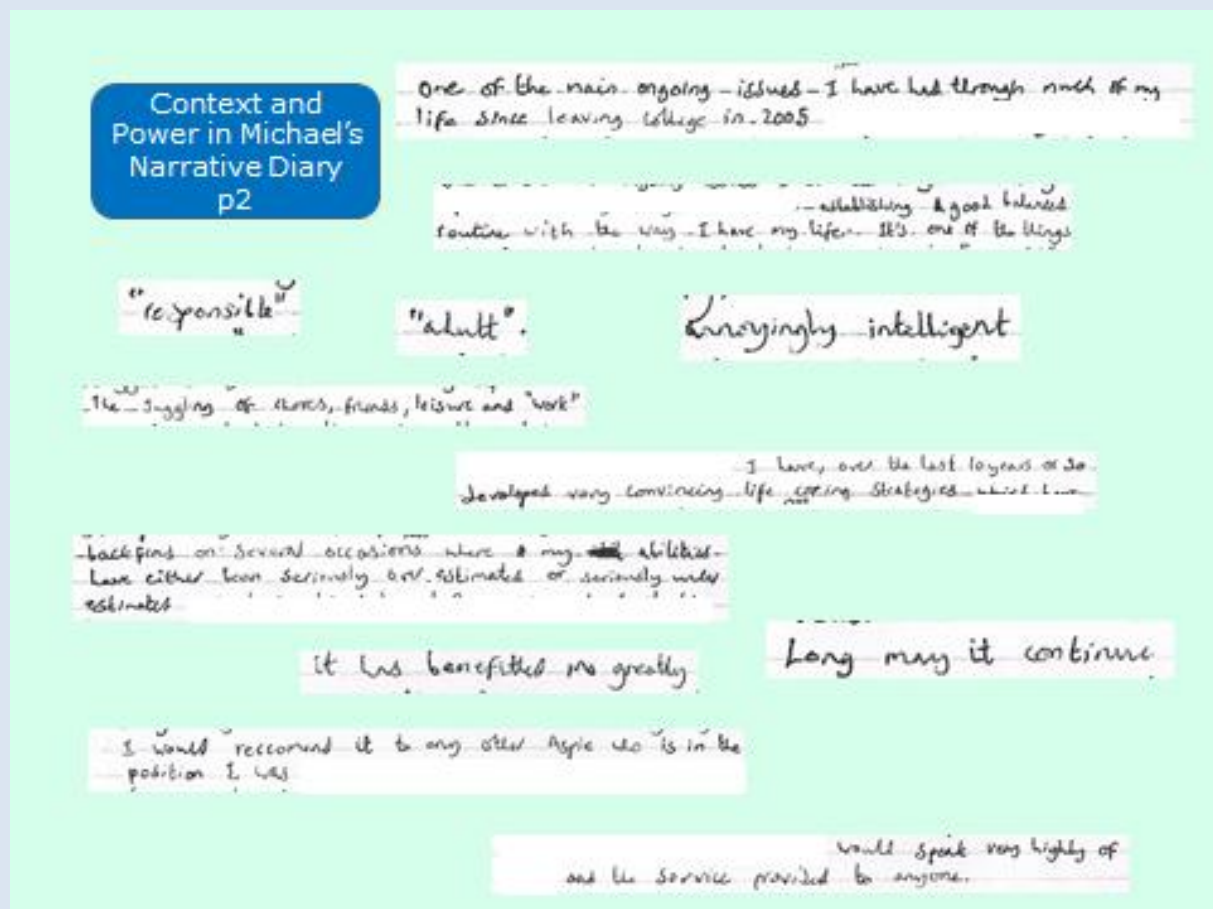


Figure 96: Context and power in Michael's narrative diary p2

Michael's data passes through contexts of life since college living as a responsible adult, a decade of developing coping strategies and the most recent context of receiving support. Throughout these, there is a shifting of power. The data speaks of 'establishing a good balanced routine', yet as an audience, I am unable to understand what he means by this or whether somebody has told him he needs one.

The issues of 'responsible' and 'adult' suggest that, as they are in quotes, they are identities imposed on him, by himself or others, with expectations attached. The identity of 'annoyingly intelligent', could be an

identity imposed by an outsider, who felt less powerful in Michael's company in certain situations, but the word 'annoyingly' can raise the question as to who is annoyed by his intelligence and in what contexts. Having taken the power to develop strategies to cope with situations that are potentially disempowering Michael stories a relocation of power as he is misunderstood in some way.

Following some support, Michael asserts his agency by recommending the service and the named support worker to other Aspies in similar situations to his. His recommendation of the service is critical, since he was in receipt of support and the service was being evaluated.

Image p3

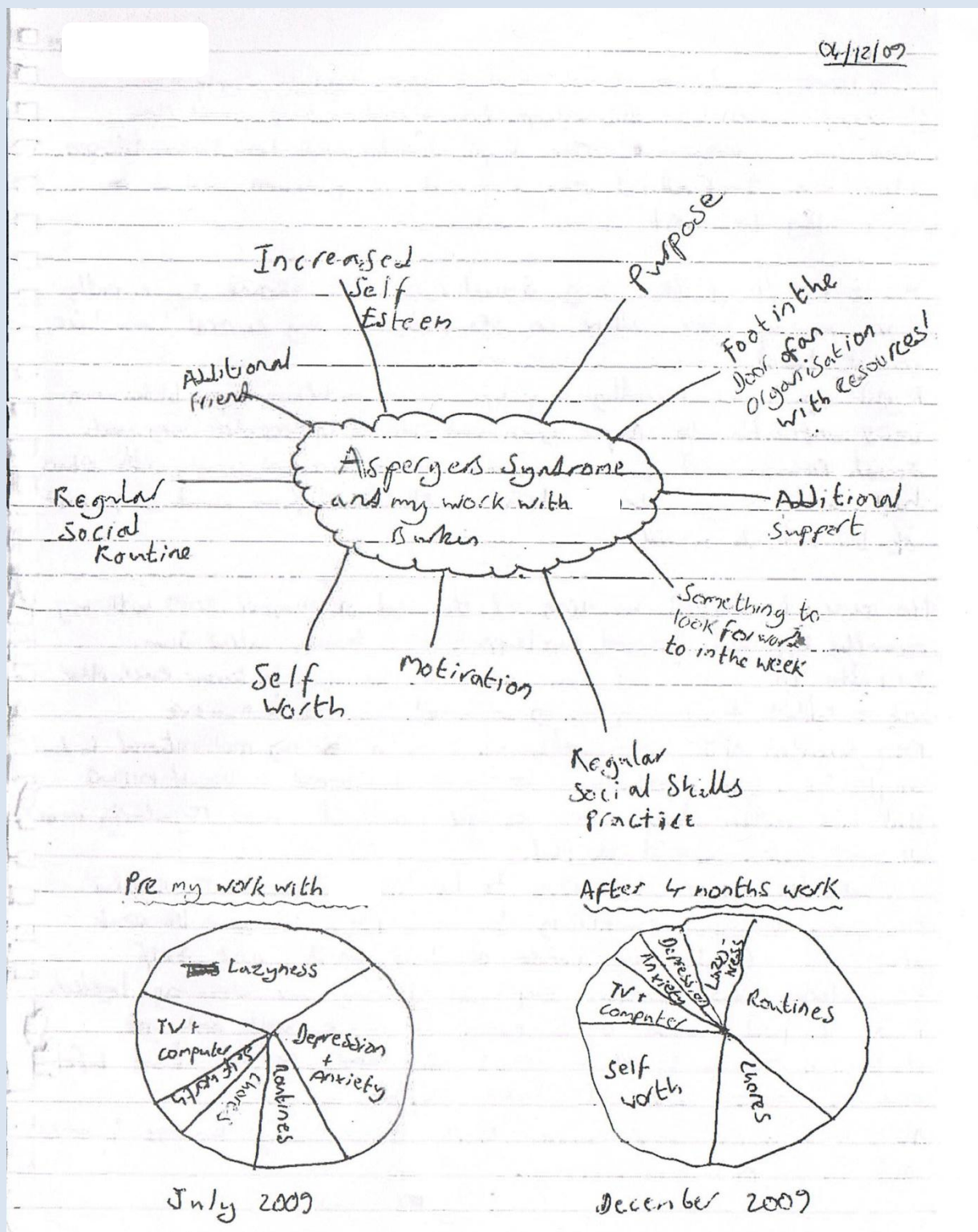


Figure 97: Michael's narrative diary p3

Summary of Michael's narrative diary data p3

Feelings and thoughts

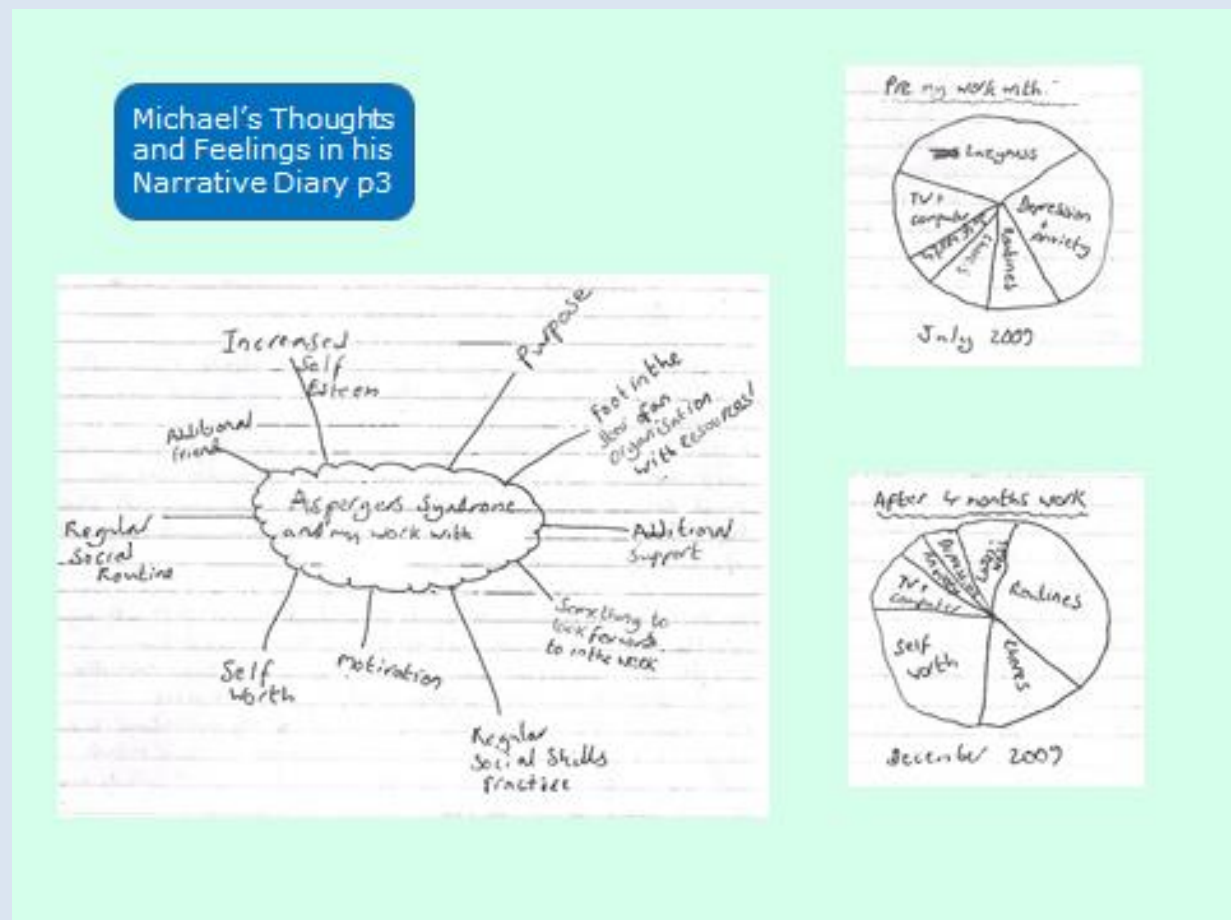


Figure 98: Michael's thoughts and feelings voiced in his narrative diary p3

In the final section of the narrative text, Michael uses diagrams to story his support with his named worker around his Asperger syndrome identity. Plots in this story relate to what is making his life go well, and have a wellbeing flavour. This negotiated support has enabled Michael to move his life approach to one of wellbeing as opposed to a focus on distress, and the storyline includes people, resources, structure and a focus, all of which form part of this narrative plot.

The second and third diagrams depict Michael's present and recent past. The two pie-charts enable Michael to reflect on these two different moments in his life and to story his past prior to support, with a predominantly sedentary lifestyle, characterised by depression and anxiety and a lack of self-worth. This is followed by a different story of wellbeing following four months' support, and Michael stories his life as being more positive, with some organisation and purpose, and where he is beginning to separate out his past and present feelings of anxiety and depression.

Michael's use of this medium has enabled him to story life events chronologically and to visualise images and adapt them to explore different messages.

Identity and wellbeing

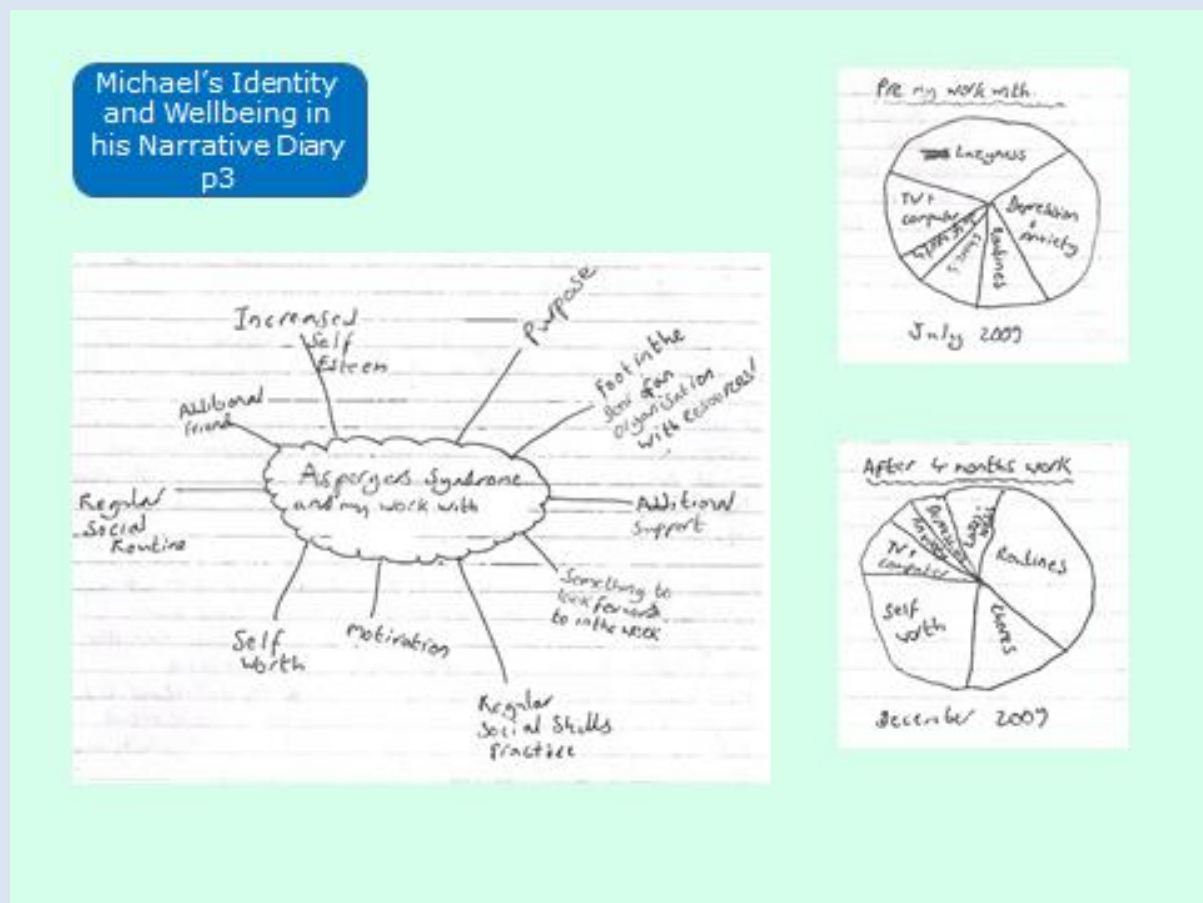


Figure 99: Michael's identity and wellbeing in his narrative diary p3

The focal point of the narrative on this page is Michael's identity of Asperger's Syndrome and his work with a named support worker. Around this, he places a detailed narrative of wellbeing that has arisen as a direct result of this support work. This relates to both hedonic and eudaemonic wellbeing and shows potential for future development.

In this section of Michael's narrative, there are two main features characterising the pie-charts which immediately grab my attention. The first is the apparent switching of the 'laziness' and 'routines' sections

following support, and the second feature of interest is the separation of 'depression' and 'anxiety' in the second chart. The progression between the pie-charts shows that mental distress and a restricted lifestyle have been replaced by activities that perhaps have more meaning to Michael.

Context and power

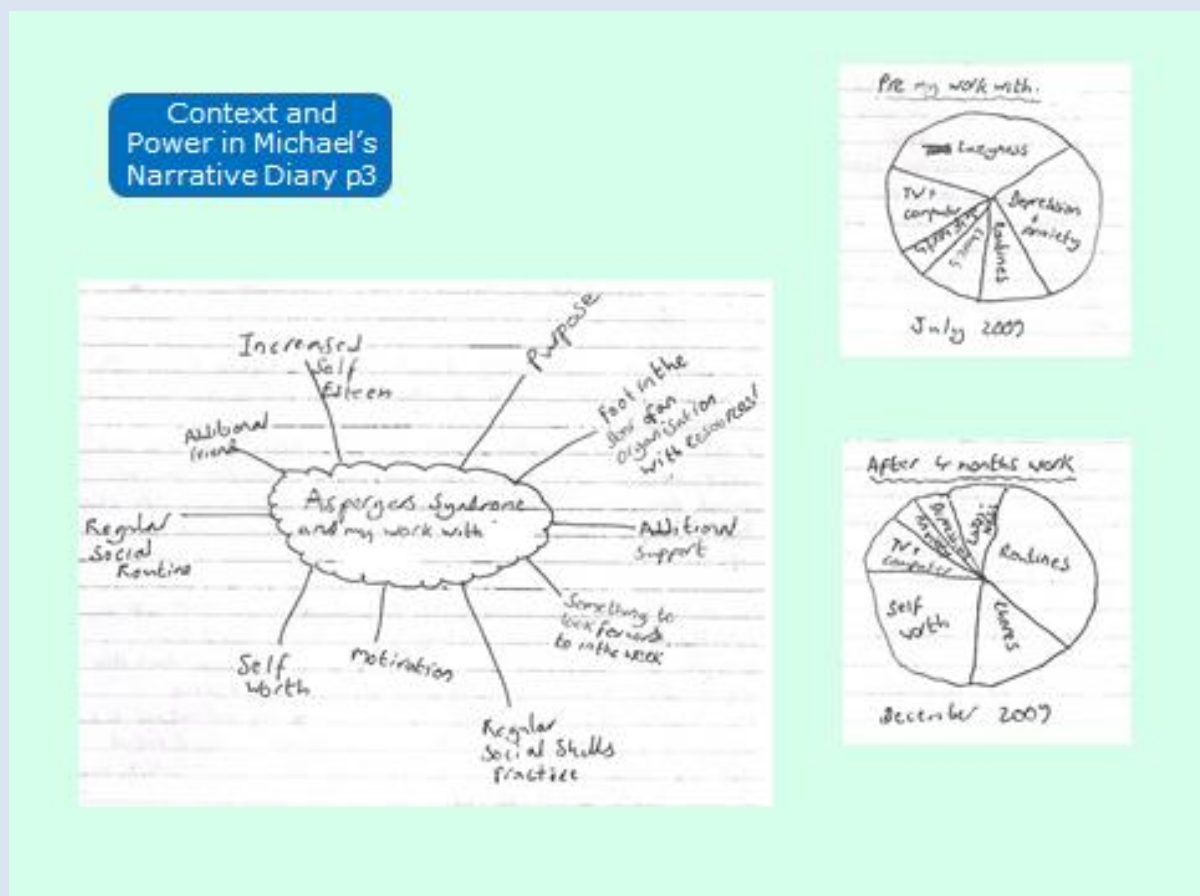


Figure 100: Context and power in Michael's narrative diary p3

Michael's storying of context is seen pre-support, and the support covered over a period of four months. His agency is demonstrated here as the person receiving and voicing his support, and he has taken the opportunity to name his support worker twice. In the main diagram, it

appears as though he is narrating his support worker as an additional friend. It is unclear whether the support worker's visits are the 'regular social routine' mentioned, or whether the support group that he attends as a result is what he is referring to, and this narrative text alone is insufficient for me as audience to determine.

Importantly, in the context of this support, Michael is storying increased wellbeing and an interest in social activity that was previously absent, and this is linked with a sense of purpose in his life and an organisation who are in a position of power to deliver further support. The pie-charts, also begin by naming his support worker, but as he stories his support 'with' her as opposed to being delivered 'by' her', I can understand a sense of his involvement, and therefore shared or negotiated power from the outset. Data on page 1 of his narrative states that the support worker challenged him and that this was good. This again suggests a negotiated power to tackle situations that were proving obstacles to Michael's wellbeing.

Collage

Draft collage process

I met Michael at a support group for around twenty-five autistic adults and family members, that I was invited to attend. The group seemed to address a dual agenda in relation to provision of a social space for autistic

individuals and their family to meet, exchange news and run activities, and was held at a day centre for people with Learning Difficulties. The atmosphere was uninspiring, with gloomy artificial lighting and a lingering institutionalised smell of stale food and urine, and I wondered if it had a similarly uninspiring impact on others around me.

Social Care staff present asked me to introduce myself and the collage activity, and I introduced myself as a PhD researcher at the University of Birmingham involved in evaluating their support service established by Adult Social Care for autistic adults in the region. Realising that this located me in a powerful position, I also highlighted my more personal interest in and experiences of autism to provide some sense of balance, emphasizing location of the autistic voice and listening to their experiences. I then introduced the collage activity as one which they might wish to participate in individually or alongside others, to story their experiences and tell me about their support requirements.

In finding his 'own place', Michael had positioned himself at the far side of the room away from the activity such that I assumed that he was disinterested. However, Michael's mother was present and facilitated his joining in by explaining to me that I would need to enter his defined space and invite him, as Michael had specifically told her how keen he was to participate. In addition, I was able to reflect on whether Michael had

moved to the edge of the room to manage his feelings, which perhaps were in relation to sensory and social overload. At times it can be extremely enabling for familiar people to facilitate the building of a communication bridge so shifting the location of power within a specific context. This does not only relate to autistic individuals.

Michael chose to produce his initial collage individually on a table away from others, and took immediate ownership of the process. He told me that he wanted to go straight into the collage production with no preparatory mind mapping as he was clear about his message. I found it interesting that he had prepared himself for this activity and interpreted this as an eagerness to voice perhaps previously unvoiced opinions. I also wondered whether he had reflected on a possible image, as his bold statement in the middle suggested a real sense of agency, drawing me in to absorb and listen to his requirements.

Image of draft collage

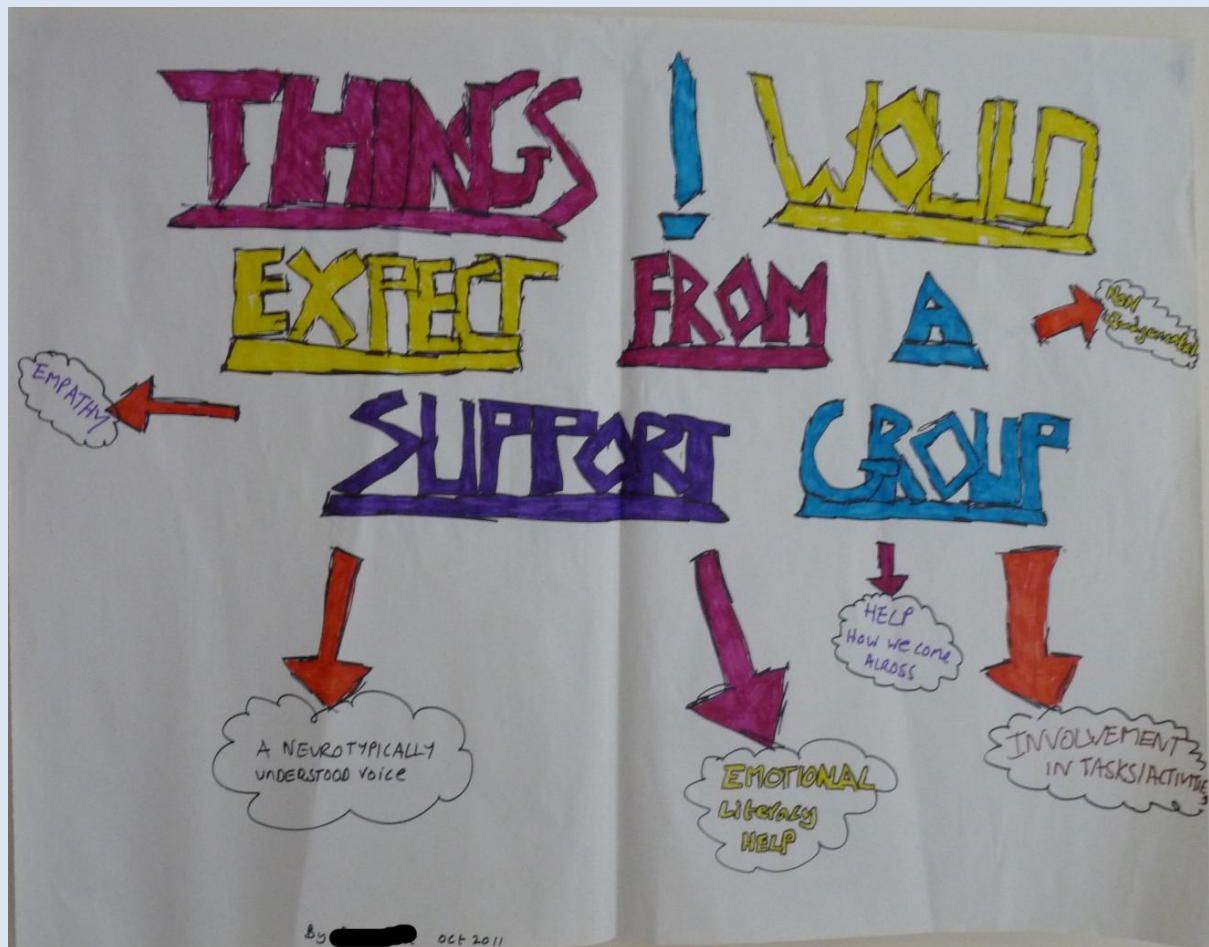


Figure 101: Michael's draft collage

The data in this draft collage are made in the form of statements, which emerge from a central message about expectations.

Summary of draft collage data

Feelings and thoughts



Figure 102: Feelings and thoughts voiced in Michael's draft collage

The data reveals expectations of a support group, and there is the 'othering' of neurotypicals. Feelings about being judged and not being understood come across and are accompanied by a request for help to express himself, particularly in relation to his emotions. This request locates Michael as part of some community as he expects 'help how **we** come across', yet the group composition remains unstated. The fact that

he expects involvement in tasks and activities also suggests that either does not presently occur or not in the way he wishes.

Identity and wellbeing



Figure 103: Identity and wellbeing in Michael's draft collage

The othering of neurotypicals suggests that Michael identifies differently, although this identity is not stated. The data speaks of a support group, and combined with other data around expression of emotions and thoughts, being understood, a non-judgemental approach towards him and inclusion in activities, these conjure up an image of poor hedonic and eudaemonic wellbeing. The data may allude to past experiences, which

are now being addressed by a support group and which allow his identity to come to the fore.

Context and power



Figure 104: Context and power in Michaels' draft collage

The data from Michael's draft collage highlights that it is set in the context of a support group. There are a number of possibilities for the location of power. It could be in the hands of those running the support group or if different, in the hands of the membership or a negotiated power between those running the group and the membership.

The statements by Michael suggest that he locates a certain amount of power in the hands of 'others' in terms of helping and supporting, and the data demonstrates a sense of agency as Michael uses the word 'I' and places his expectations around his central message. In addition, his use of the word 'we' implies a group membership, which raises the question of group cohesion around these anticipations. 'Outsider' power is demonstrated as 'involvement in tasks and activities' indicate that this has not necessarily been happening and that both he and those in his group membership expect it.

Reworking the collage

As Michael was pleased with his achievement, I asked him if he was interested in making this a more durable piece of artwork, and so he selected a number of different pieces of coloured card that I had brought. Collage was a new activity for him, and the thought of using different materials proved to be a good focus and one which was challenging. This complimented information that he had provided in his text. The session stopped at this point.

Process

Michael created his collage over three two-hour sessions, and the venue used for the second and third sessions, where he reworked his collage and produced the final image, was an office space housing various social care teams. We had a quiet room with natural light, and apart from some

staff walking about serving to remind us that the space essentially belonged to authority figures, we were undisturbed. This created a more relaxed atmosphere as it addressed some issues relating to hypersensitivity, and as a result appeared to allow Michael to take more control over the narrative production.

For the second session, Michael arrived with his mother, girlfriend and a support worker, thereby introducing more of an immediate audience and potential layers of power influence to his activity. The fact that his girlfriend had joined him suggested to me that the activity may have been discussed as something that was of interest, maybe even fun. Both engaged in the activity, extremely focused on the task. Michael and I worked together to create the background out of card that he wished before he continued individually, painstakingly cutting around the images he had drawn. The impression I had was that the images used to voice his opinions meant a lot to him, and it was almost as though taking care not to tear the paper represented the control he was taking back from non-autistic others, giving him a sense of agency. Once cut out, Michael began to re-arrange his text on the card.

The re-processing of information required by the production of an altered image became a more complex activity for Michael. Consequently, I was concerned about the possible negative impact that this and the imposed time frame may have had on his wellbeing. In contrast to my

expectations these did not appear to affect Michael's enthusiasm, as the activity had provided him with a new challenge, which tapped into his creative and expressive skills regarding accuracy and precision.



Figure 105: Michael's reworking of his draft collage

Final collage process

The way in which Michael tackled the process of his final collage piece is an example of how co-production can work well. Michael remembered that the other images would not fit, so we discussed whether he wanted to extend the image to both cards and reposition the arrows accordingly.

The discussion seemed to enable Michael to retain his sense of agency in order to develop his narrative as he wished.

It was evident to me that the reworking of his image placed a lot of demands on Michael as he needed to go outside several times for a cigarette: "to have a break" and "to de-stress". I reflected on the fact that being given an opportunity to have a voice is not always a stress free process. Nevertheless, Michael was able to maintain his sense of agency, and each time he re-entered seemingly refreshed and keen to continue the activity with renewed focus. This indicated to me that this activity provided Michael with a sense of purpose, choice and agency, and that he was in charge of the immediate audience to his narrative production.

Final collage image

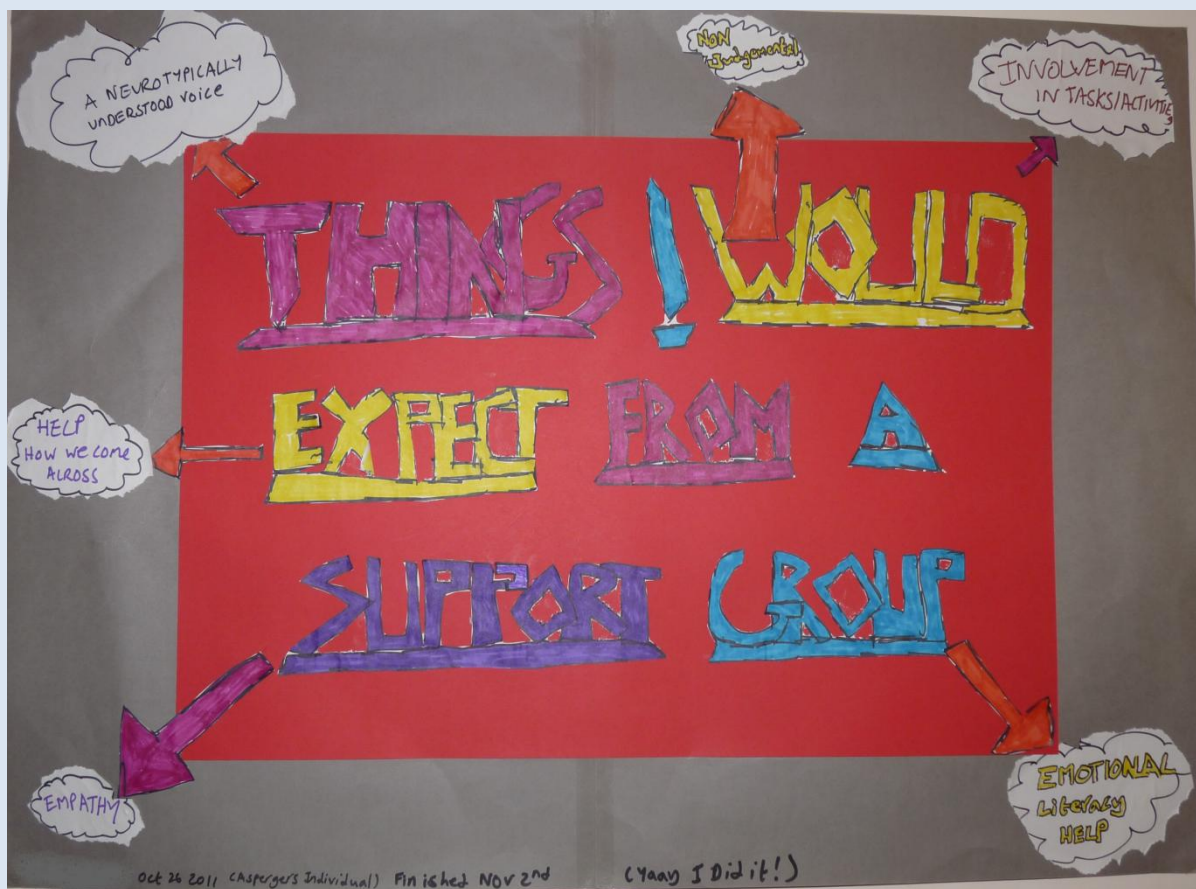


Figure 106: Michael's final collage

The final image had the centre message placed on one piece of card, and Michael was then able to shift the arrows so that they led from this to the newly ordered messages around the outside. In addition, there was room for Michael to tell me about his identity, the length of time taken to complete the task and what he felt about this. The realisation of the enormity of this task for Michael in terms of rearranging an already-formed image was a turning point for me.

Summary of Michael's collage data

Feelings and thoughts

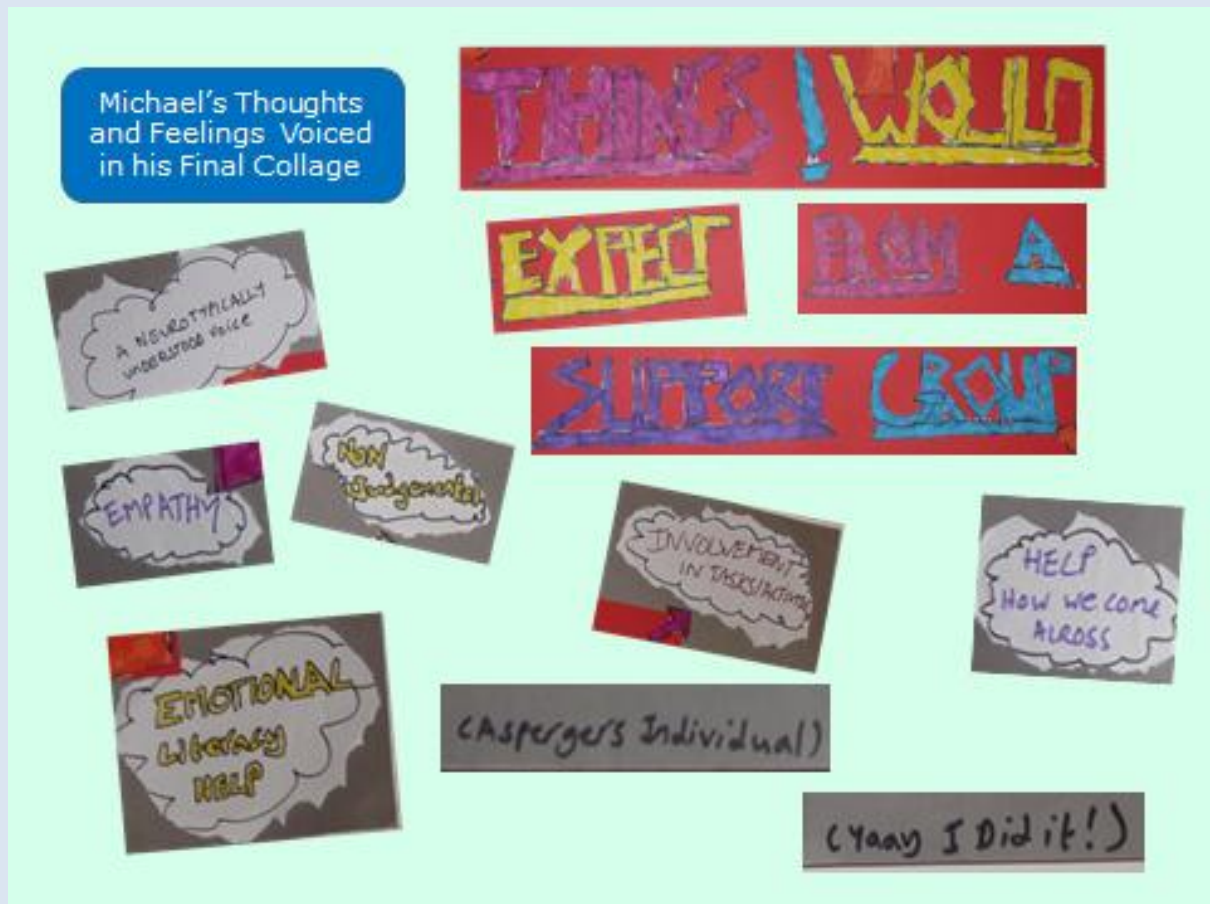


Figure 107: Thoughts and feelings voiced in Michael's final collage

As with the draft collage, the data here speaks of expectations that Michael would have of a support group. This use of tense suggests that perhaps the expectations named are not happening or entirely being addressed at the time of the collage construction. The difference between this data and that of the draft is that it has been enhanced by the voicing of an individual identity, whilst maintaining a statement about a group

membership, which may or may not be the same. In addition, he voices a sense of achievement at having finished the collage.

In providing him with space to voice his views and take control over the production, Michael was able to use collage to story his thoughts and feelings on a specific topic with clarity.

Identity and wellbeing



Figure 108: Identity and wellbeing in Michael's final collage

It is at this point in the collage process that Michael reveals the identity linked to his particular narrative, which is clearly one of individuality. However, there is still an image included in the data which reflects an identity as part of a group membership. The other data is perhaps attached to either/both of these identities, and there is a statement which is clear that Michael does not regard himself as being neurotypical. His identities call for support, help with self-expression and empathy (Milton, 2012a) and point to judgemental attitudes and his exclusion from activities, both of which may impact adversely on his wellbeing. In addition, there is an expressed sense of relief and satisfaction on completion of the activity, and this shifts his wellbeing to a more positive dimension.

Context and power



Figure 109: Context and power in Michael's final collage

This image is rearranged so that context of the main message stands out and the sub-messages are located around the side as expectations. Once all the images were fixed in place, Michael demonstrated further command of the process as he finished the piece by writing on the bottom: 'Yaay I did it!' signed it off and dated it: start date October 26th 2011 and finish date Nov 2nd 2011. He has claimed agency as an Asperger individual, also putting himself in the context of a group and sending a clear message as to his expectations about his support requirements.

Furthermore, he is challenging the power dynamic, which he perceives to be in the hands of others who exclude him from tasks and activities.

Michaels' mother's narrative (anonymised as Sally)

Process

In the storying of Michael's experiences, I had a wider range of contextual information provided by his mother in the form of a narrative text handed to me by Michael's support worker. Sally's narrative is written for someone who will perhaps be able to act on the information provided and states that listening is an essential ingredient to including autistic people in all sectors of society. This is a theme mentioned earlier by Brook (2014) and Milton and Bracher (2013).

The experiences storied by Sally provide an additional narrative layer, an alternative perspective and extra depth to the backdrop surrounding Michael's current circumstances. In re-enforcing and expanding on Michael's own more concise story about the impact of educational experiences on his thoughts, feelings, identity and wellbeing, Sally stories the struggle faced by many parents in finding a supportive school. This struggle ended with Michael stepping into a world where he is still unemployed, and where his parents have concerns for his future wellbeing and opportunities.

To Whom It May Concern

①

June 2010

My son is 27 years old. He was diagnosed with Asperger's Syndrome when he was 16. Until that time he had "Jeffrey" in mainstream education. After 6 years at various educational establishments and a year in temporary accommodation, he moved into the rented flat where he still lives. Over that period he has been gradually learning to manage his own household, but he does not have a job, and is still very dependent on his father and myself. At least one of us sees him daily. Last year (2009) he was invited to be part of the interview panel for the appointment of an Autistic Service Broker for as a potential service user. I was also involved, supporting him. He would not have been able to get to this meeting on his own, but with support he surprised me at how useful and constructive his contribution was. It was good to be reminded that my parental protectiveness, coupled with anxieties, could blind us both with regard to his abilities. After her appointment began working with him, visiting him once a week at his flat. In the first instance he would not see her without my being present, but he soon managed to establish a good rapport with him, and after that I was only there when the vexed question of money management was first discussed!

Figure 110: Michael's Mum's narrative diary p1

Summary of Sally's narrative diary data p1

Feelings and thoughts

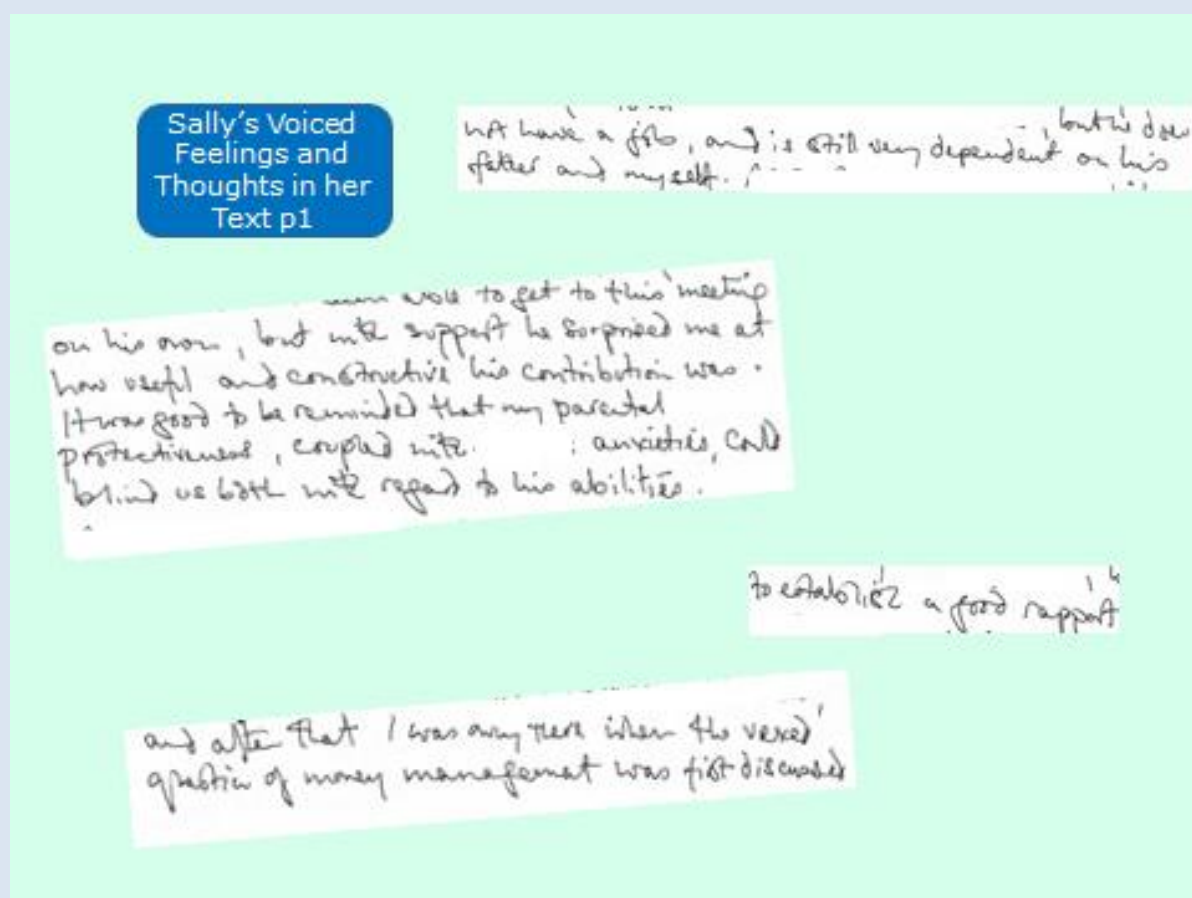


Figure 111: Sally's voiced feelings and thoughts in her text p1

The images here introduce Sally as a carer/support worker for someone. Whilst Sally reflects on her [perhaps natural] protectiveness as a parent, she voices positive thoughts about her son's abilities that had been masked by her protectiveness.

The image of a 'good rapport' suggests that communication may be an issue in some way, and Sally also mentions a concern about money

management, but I am unsure whether this or her son's struggle to deal with money is a 'vexed issue'.

Identity and wellbeing

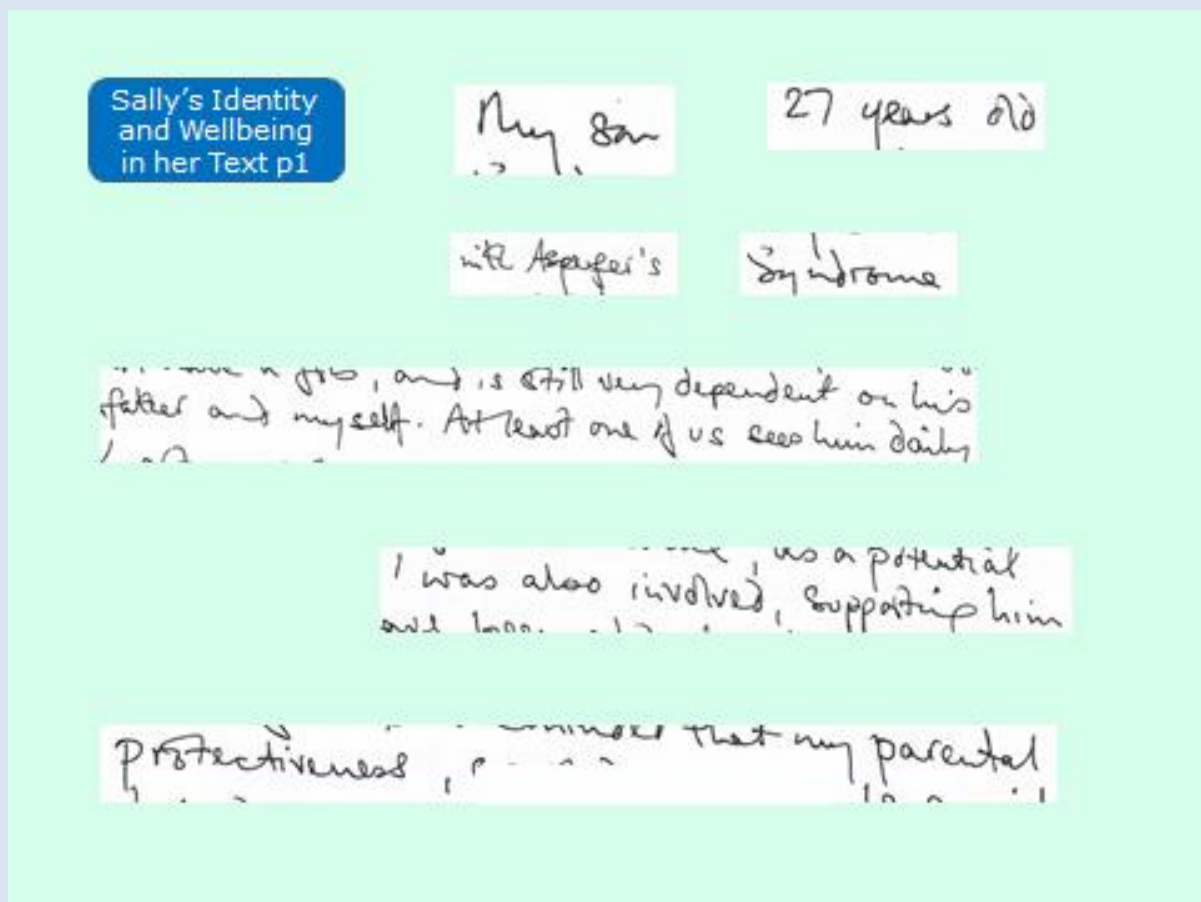


Figure 112: Sally's identity and wellbeing in her text p1

Sally's story tells of her identity as a mother of a 27 year-old son with Asperger syndrome. The storyline reflects on her son's dependency on both herself and his father, and that she, Sally, shares the provision of support with the latter on a daily basis. Although Sally stories her role in providing support, these excerpts also provide me with a sense of potential anxiety on her part as she states that she is overprotective

despite her son's age. The plots provided point to possible low hedonic wellbeing, although a sense of her involvement with her son's support gives a clue as to potentially better eudaemonic wellbeing.

Context and power

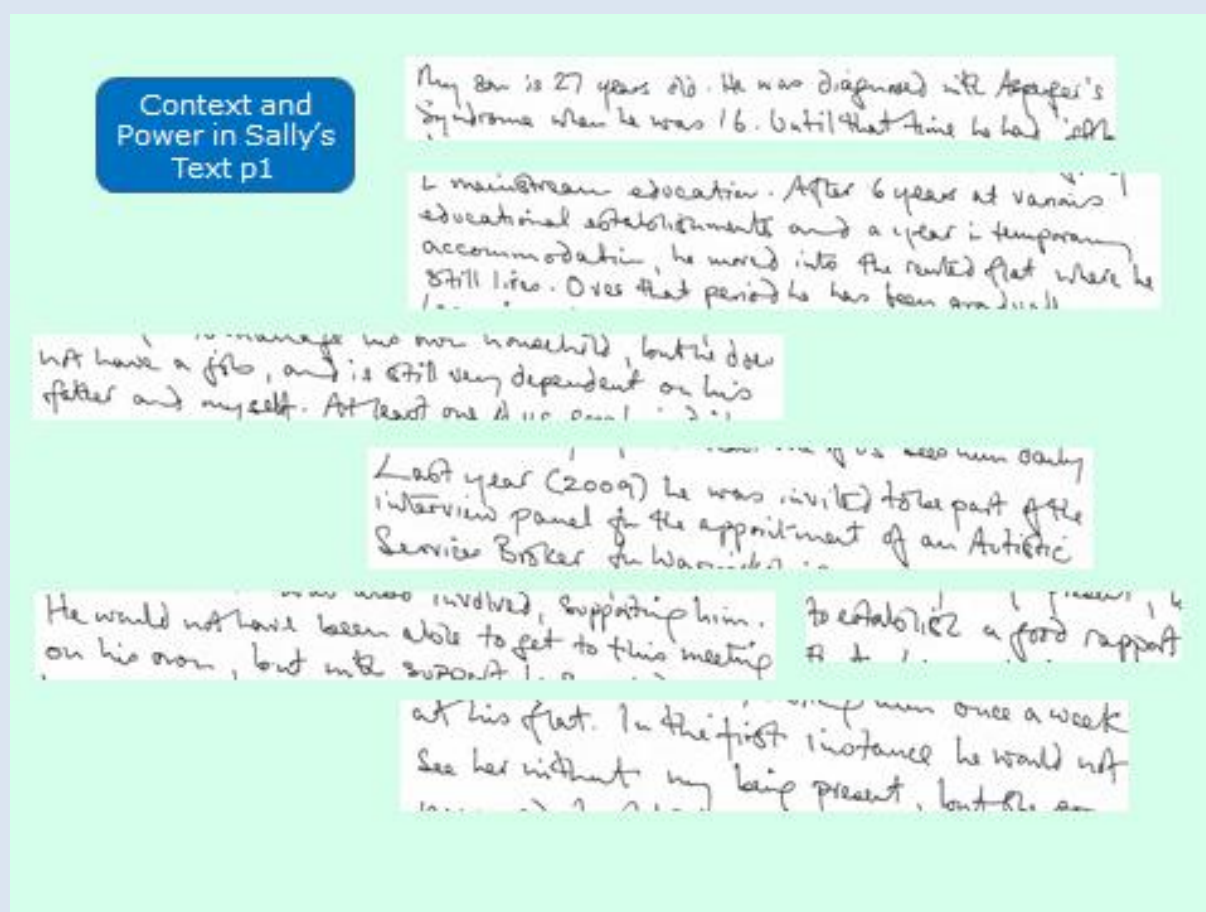


Figure 113: Context and power storied in Sally's text p1

Sally introduces the context as being around her son, who is a young adult with Asperger's syndrome. His recent history is storied as one of unstable education and accommodation, and his current situation, though perhaps more stable in terms of accommodation, is characterised by unemployment and a dependency on Sally and Michael's father. This set-

up indicates that Michael perhaps has felt powerless in a number of situations, and that also Sally and Michael's father maybe have no choice but to support their son.

The context then switches to a more positive one regarding an interview, and where Michael has been invited to take part in interviewing an 'Autistic Services Broker'. These extracts inform me that Michael required support to be in the meeting. The suggestion that a good rapport needs to be struck with Michael somewhat suggests that this is different to the situation with any other person, and more so in that Sally's presence is initially required. This again reinforces the storyline of Michael as a powerless individual in certain situations, unable to express himself. In such contexts, power is shifted to Sally to act as intermediary in the establishing of a more negotiated power.

(2)
 With her help he has been able to talk through
 what is happening in his life, and she setup a series
 of small goals for him to achieve each week, using
 a visual chart. This has enabled him to set up
 better routines in his everyday life. There have been
 numerous ups and downs as the weeks went by,
 but it is very much to credit that she has
 persisted despite considerable anxieties/stressed
 behaviour, which can be verbally hostile.

If working one-to-one with an adult on the autistic
 spectrum is difficult, working with them in a group is
 even harder. Yet this is a necessary next step
 if they are to learn more about themselves and
 others, and how to manage their relations when
 interacting with other people. Just as we need to
 learn and appreciate the different assumptions they
 make when communicating. A new support group
 has been set up. Parent carers are also involved
 with this. We have always been the facilitators
 for our children. That role should not be exclusively
 ours. We will all learn, as we go along, how to
 communicate effectively with each other.

involvement has been beneficial to the
 whole family. For the first time we are not
 totally alone in supporting an adult son who
 needs as much attention as a child. As a group

Figure 114: Michael's Mum's narrative diary p2

Summary of Sally's narrative diary data p2

Feelings and thoughts

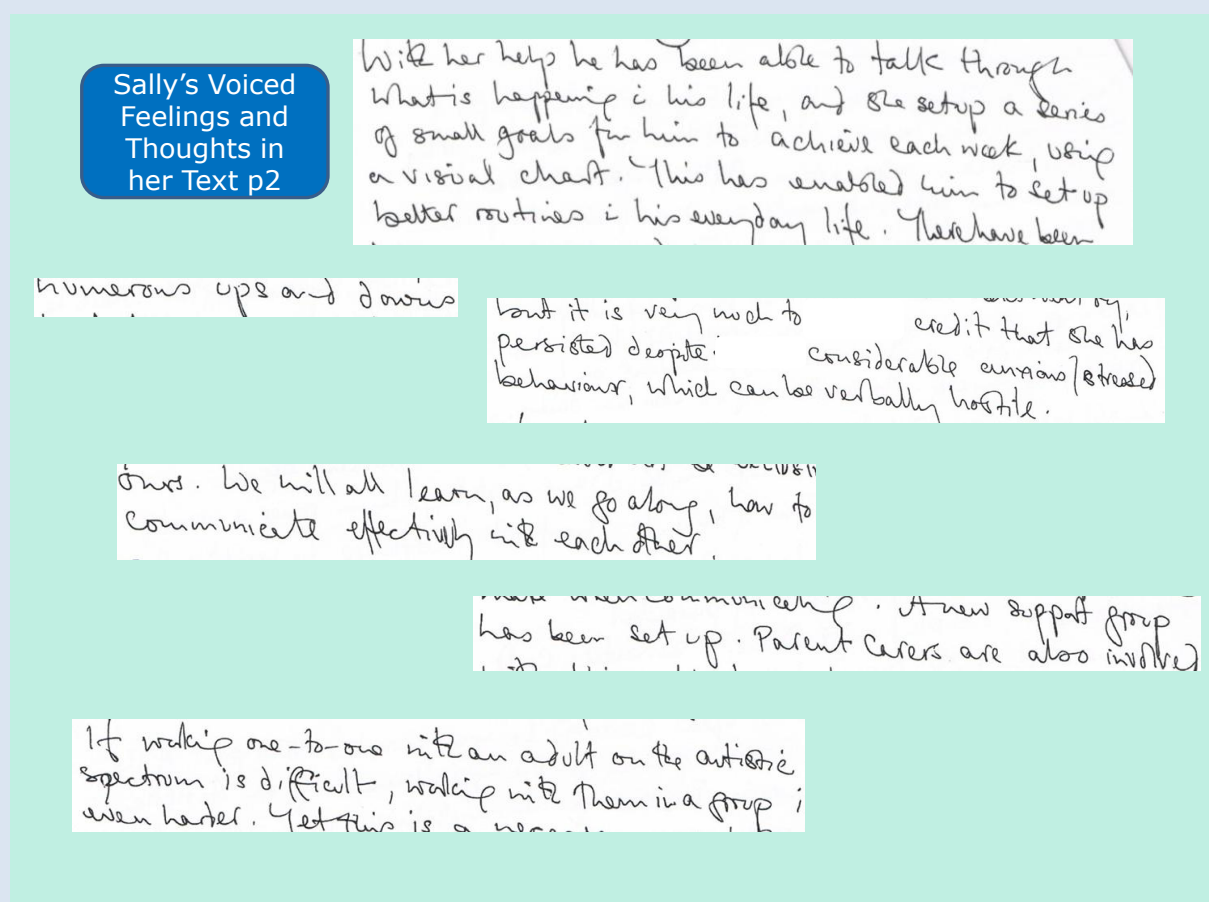


Figure 115: Sally's voiced thoughts and feelings in her text p2

This part of the narrative now moves to a focus of support given by someone working with Michael to simplify his life in terms of setting small achievable goals using a visual tool. I am able to learn that the process was not necessarily a smooth one. Sally attributes the success to her son's support worker, who continued despite Michael's 'verbally hostile behaviour'.

In the context of a support group, Sally's story becomes one of learning how to communicate effectively, and she situates herself as an 'outsider', again mentioning the existence of communication challenges faced by non-autistic people.

Identity and wellbeing

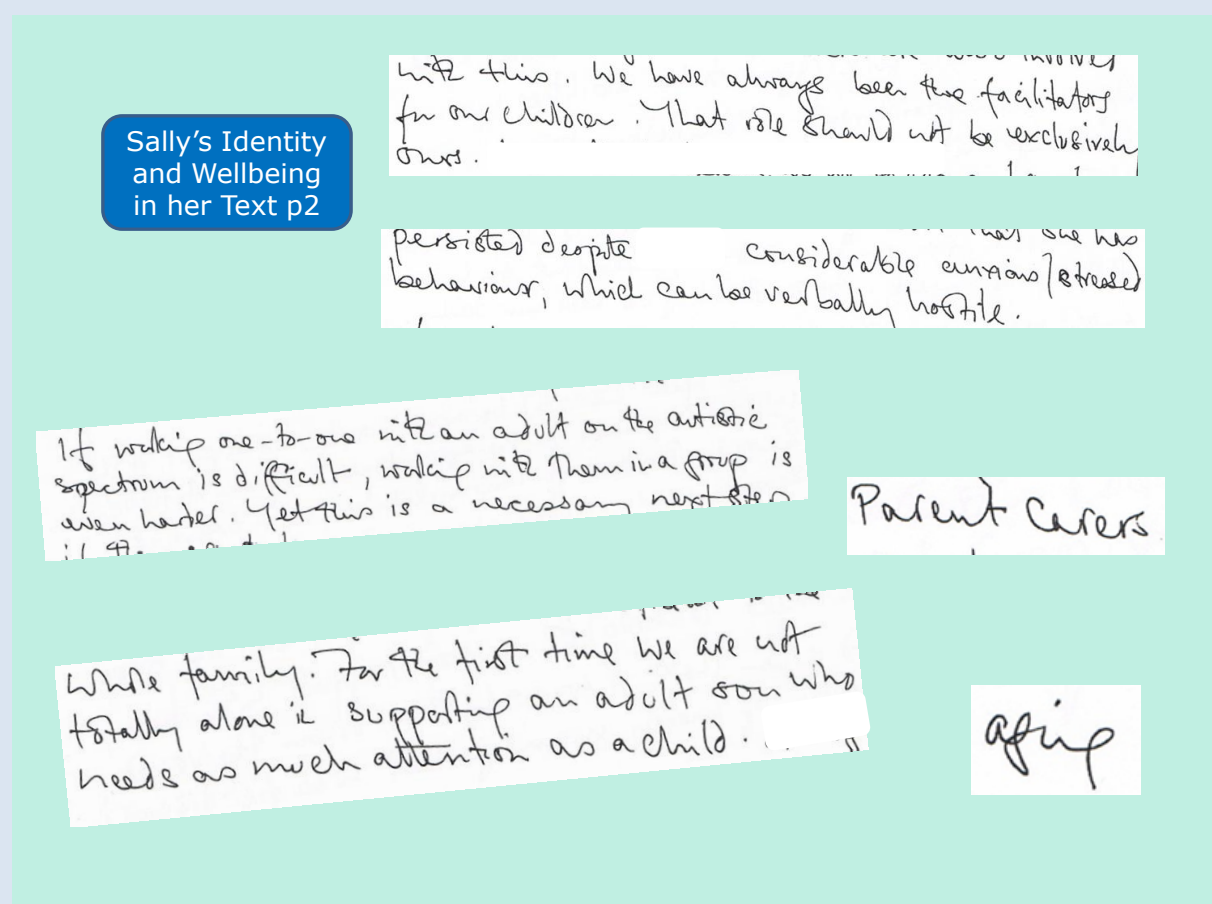


Figure 116: Sally's identity and wellbeing in her text p2

Placing herself as perhaps a reluctant facilitator for her son as she is a parent carer, Sally also mentions the fact that she is aging. She sees the role of facilitator as belonging to someone else or to be shared.

In terms of her wellbeing, the fact that she stories Michael's behaviour as being verbally hostile at times suggests that she may have felt upset or demoralised either for herself or her son. This is placed in a framework of Michael being difficult to work with, and the implication being that this might have proved a challenge to her wellbeing.

A turning point occurs when support is provided to Michael, as Sally stories a sense of relief, 'for the first time we are not alone', and this introduces a positive theme to her wellbeing.

Context and power

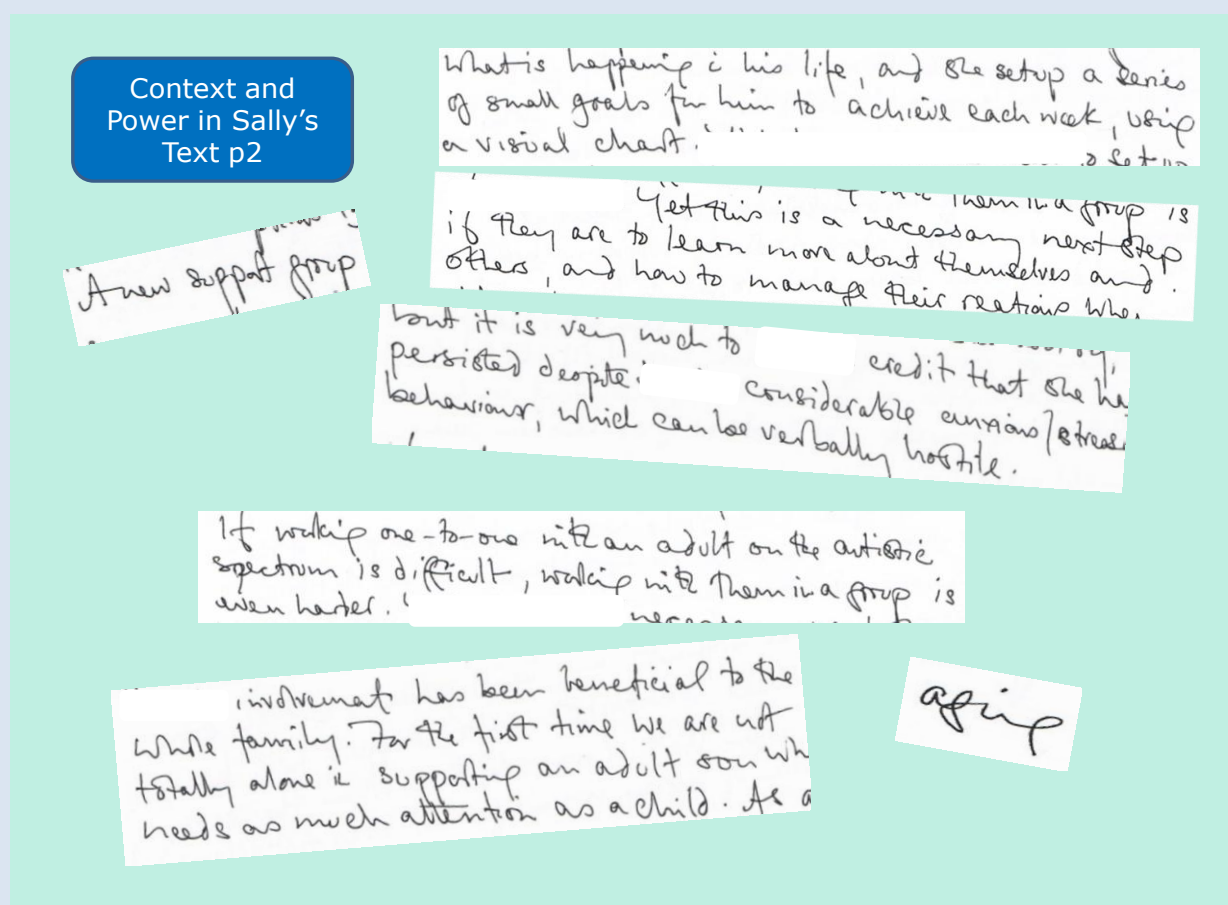


Figure 117: Context and power in Sally's text p2

Sally takes control of both her storyline and her son's identity in terms of narrating him as a member of an 'othered' group, and she stories them both as needing to learn about themselves. The data illustrates her power over this storyline as Michael's possible struggle in dealing with the support worker and NTs are not acknowledged (Milton, 2012a).

In this part of Sally's narrative, she is clear about a stepped approach to helping autistic people learn about themselves, and there is no real sense that this might need to be a two-way process. Sally's power over this story is such that autistic people are presented as 'difficult' and with a lack of self-awareness. Michael's challenges are presented as him being childlike and no skills or positive attributes are provided in this section. The language resonates with medical model terminology, with a focus on problems situated within the individual as opposed to social barriers to inclusion.

③

Parents, it is very important for us to know that
 has a lifeline to a service which understands
 him. His difficulties are invisible, which makes
 the handicap harder, and what is more, the
 greater the efforts he makes, the more invisible
 they become, and yet more is expected of him...
 At the same time, he has much to contribute.
 Continuing support is necessary to enable him
 to fulfil his potential. I feel that this first
 official step by _____ into working with,
 and understanding the complex world of autistic
 adults has been a wonderful step forward, and
 I pray that it will be able to continue making
 this enormous difference to the lives of all the
 families in the county who are affected by
 autistic spectrum conditions.

Figure 115: Michael's Mum's narrative diary p3

Summary of Sally's narrative diary data p3

Feelings and thoughts

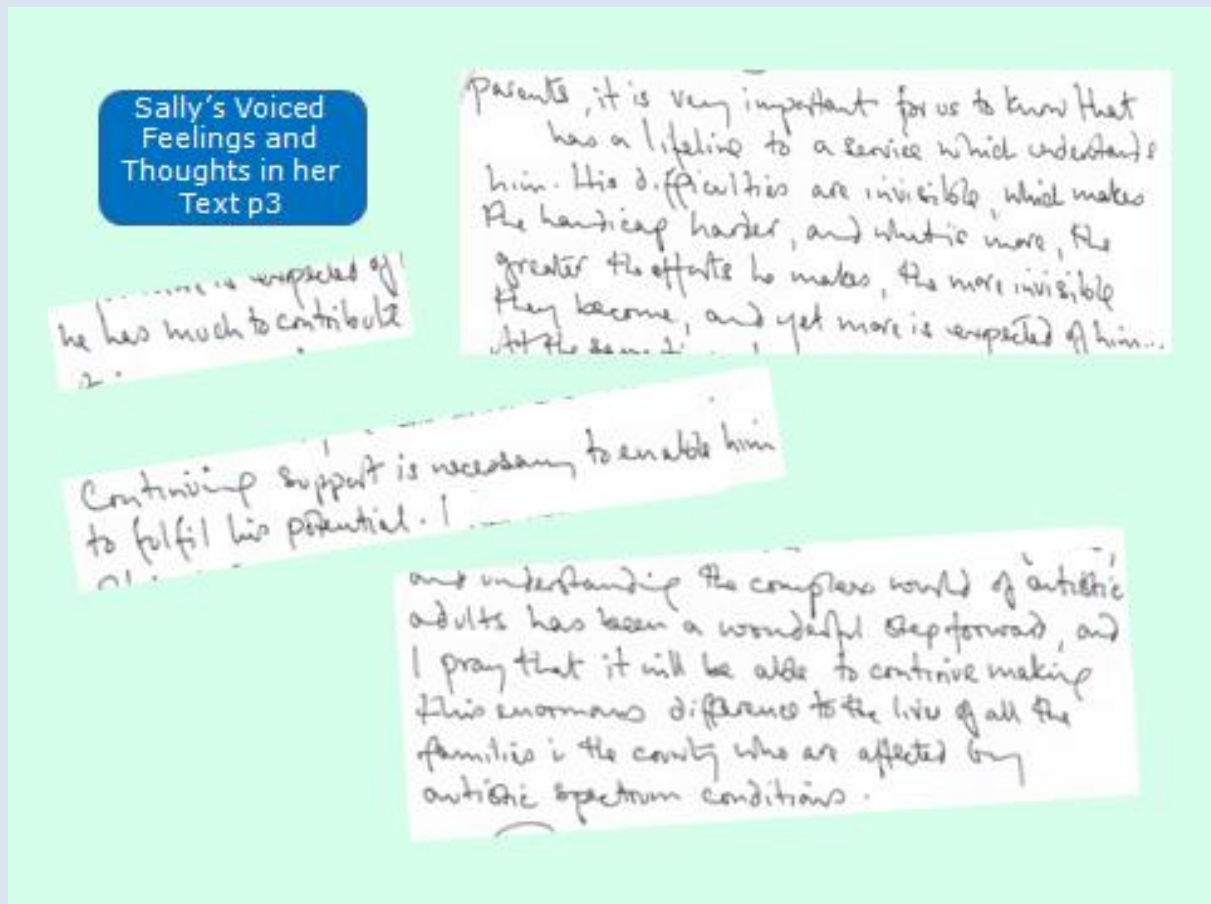


Figure 116: Sally's voiced thoughts and feelings in her text p3

Sally voices concerns about her son's future, and in so doing stories herself and his father as being his current 'lifeline' as they understand him. There is a separating of Michael's difficulties and his being autistic, which Sally voices using medical model language, namely 'handicap'. She tells of invisible challenges, which result in Michael's abilities being misunderstood. Nevertheless, she is of the view that he would require constant support to realise his true aspirations.

Her final narrative concerns her perception of autism as being something that 'affects' the lives of families as opposed to individuals. This storyline again places autism within a medical model framework, as indicated by language used, and suggests some sense of homogeneity as regards families with autistic family members.

Identity and wellbeing

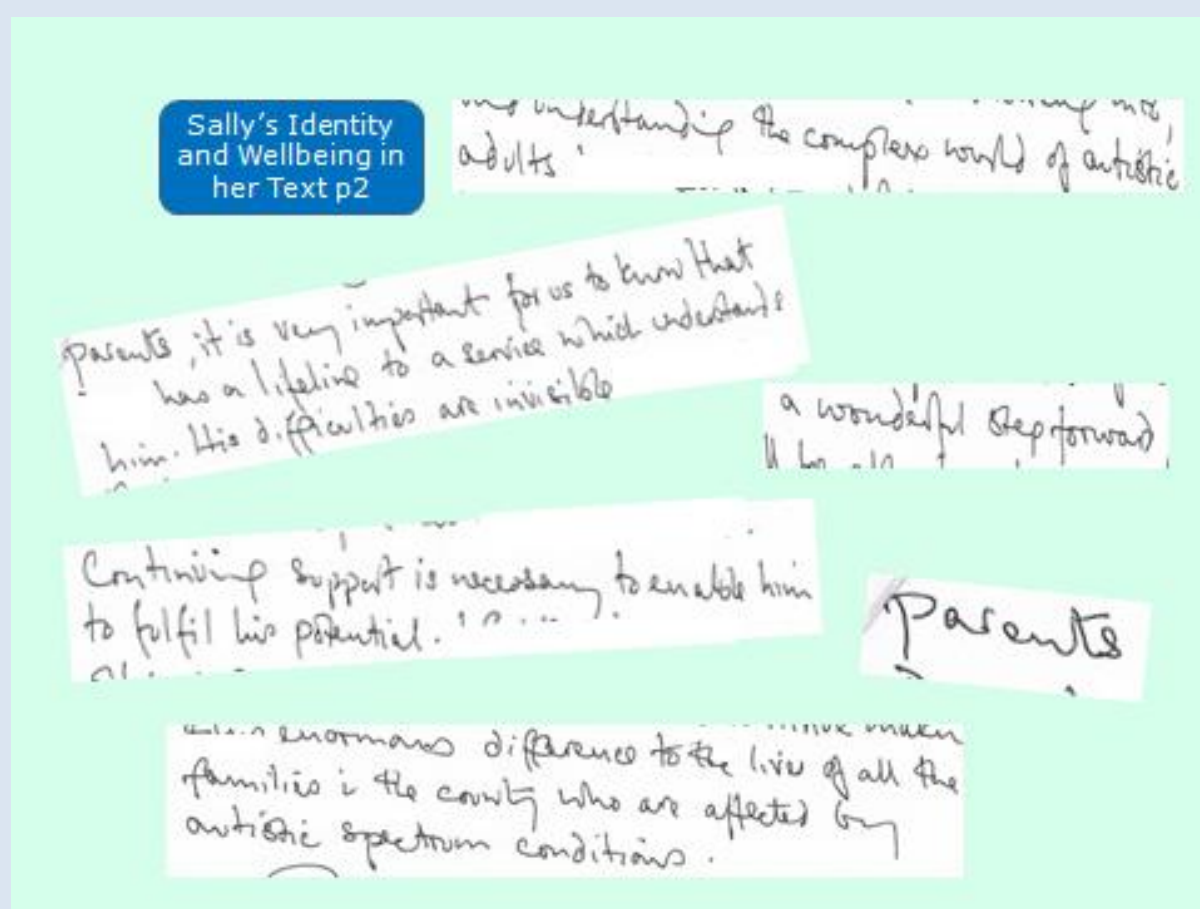


Figure 117: Sally's identity and wellbeing in her text p3

The data here tell of a mother who worries about her son's future, and she stories support or inclusive services almost as a last resort, not as a right. Sally identifies as a parent in a family 'affected by autism', a

complex condition requiring continuing support for the autistic person. As the provider of this support, Sally's implied wellbeing is possibly one characterised by worries and where a new lifeline has now emerged for herself and her husband, her son, or the family as a whole.

Context and power

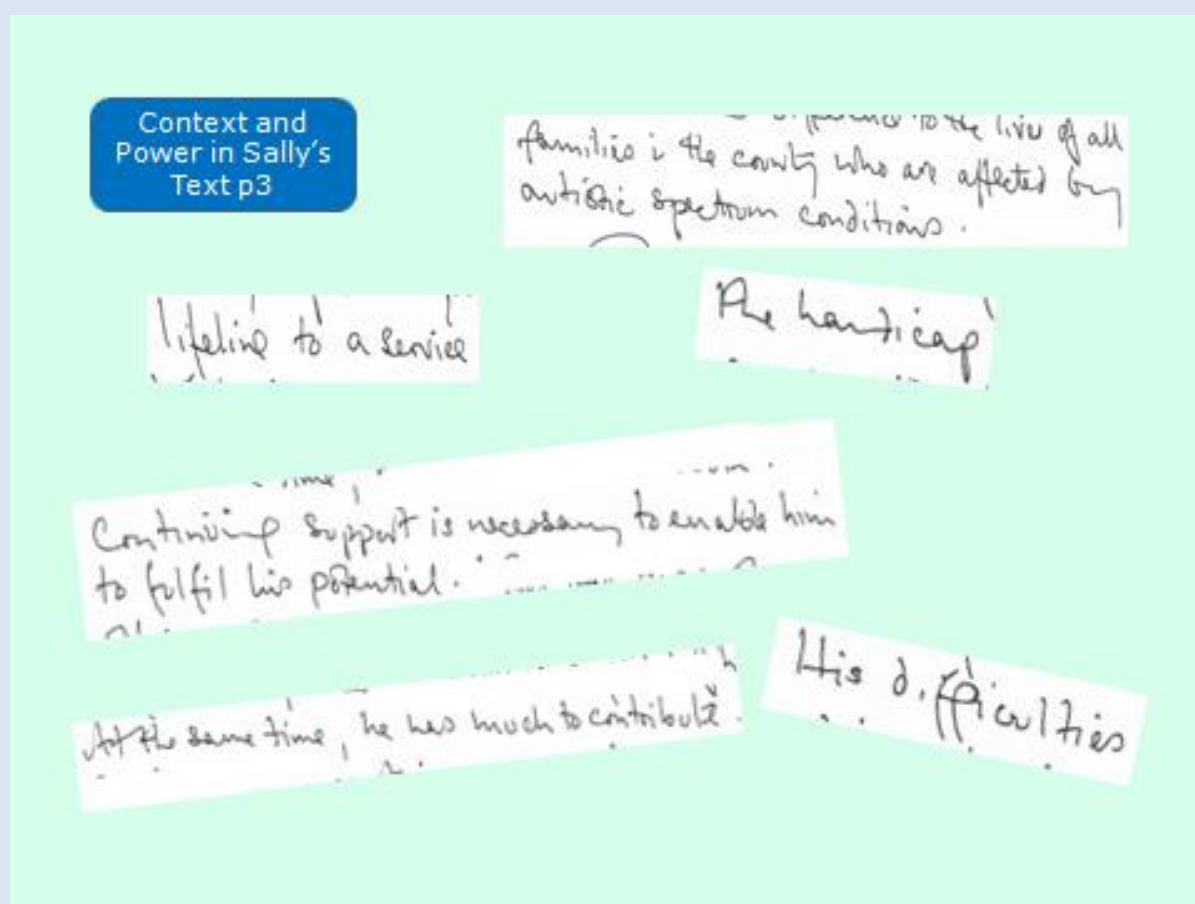


Figure 118: Context and power in Sally's text p3

Sally's data place Michael in the context of families with an autistic family member requiring support, and consequently power is skewed in favour of parents and non-autistic family members. She uses a medical framework to story his 'handicap' and 'difficulties', which desperately require help

from a service. In so doing, Sally has considerable power, using a context of dysfunctions as opposed to abilities, although there is one statement in the text where she contradicts herself and acknowledges that Michael does have considerable abilities. However, these remain untold.

Researcher analysis

Feelings and thoughts

Interpretation 1:

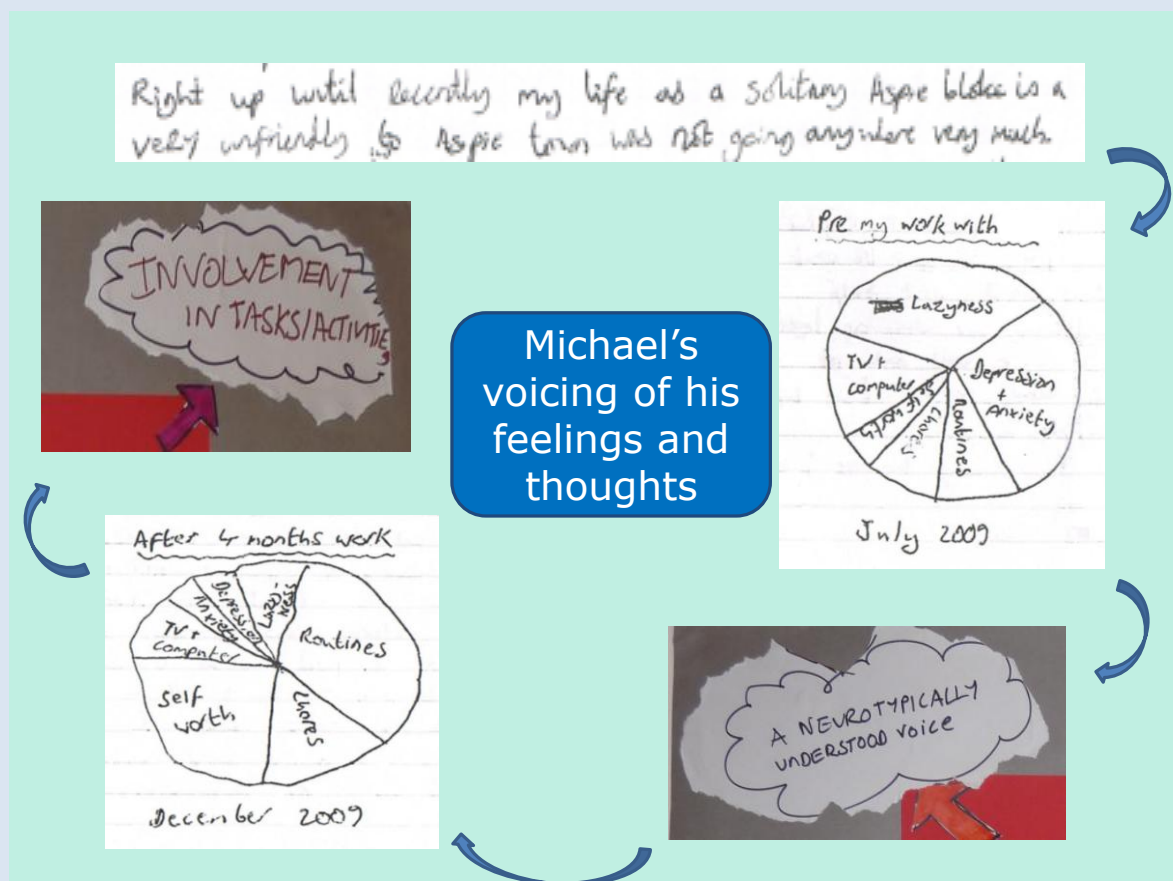


Figure 119: Media helped Michael voice impact of support

The authenticity of Michael's voice rings through these images, and this interpretation allows me to see that Michael identifies himself as an 'Aspie'. As such, he considers himself to be different from NT others, who fail to understand him. He stories the impact of this as one of mental distress, characterised by laziness and minimal activities, which demand little engagement with others so enabling him to withdraw.

There is an interesting turning point in the narrative illustrated by a complete switch around between the roles played in his daily life by laziness, anxiety and depression after he is really listened to and provided with help to structure his lifestyle.

Interpretation 2:

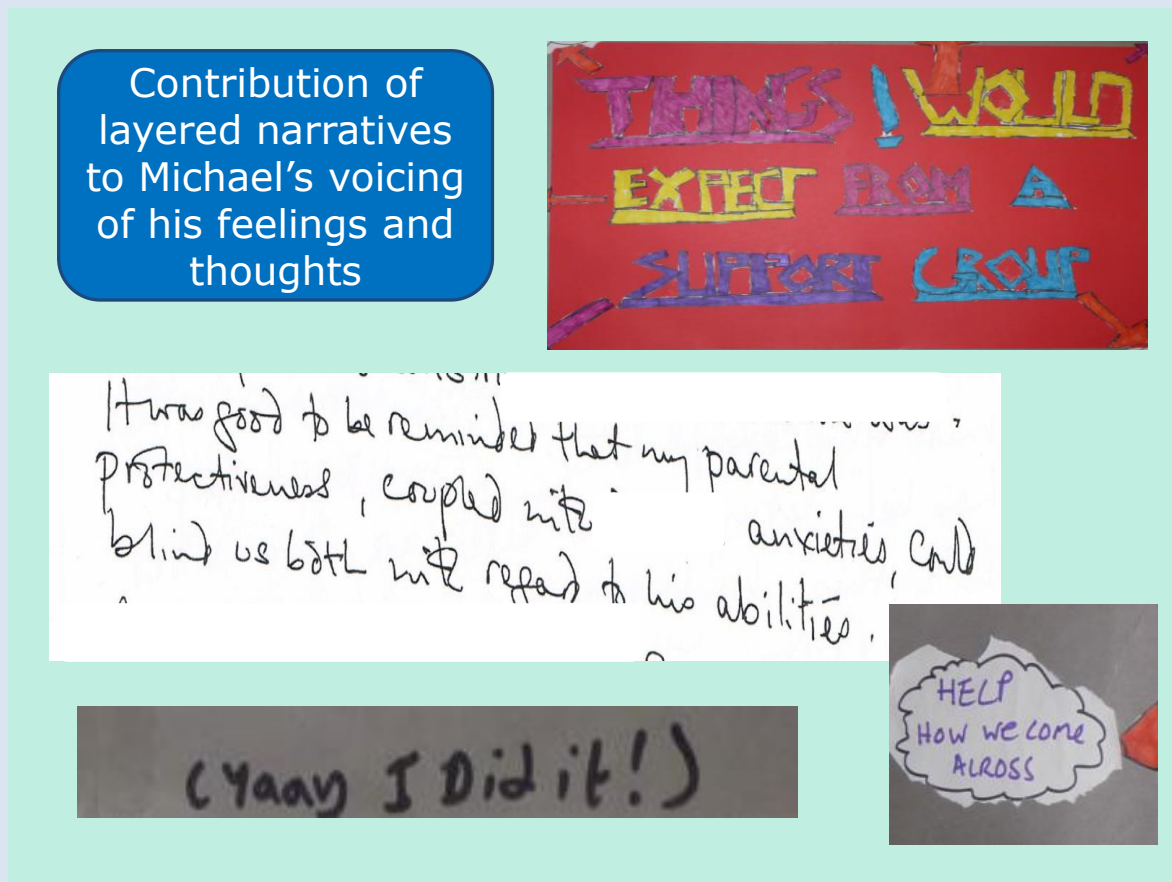


Figure 120: Contribution of layered narratives

Sally's narrative offered an additional intensity to Michael's story as evidenced by Michael's reiteration that he (and other Aspies) need help to voice their views. Sally's narrative provides an acknowledgement that parental over-protectiveness may be counterproductive, so masking abilities in autistic [adult] family members.

Michael's expectations of the support he requires demonstrate self-awareness, and despite the fact that the collage medium proved challenging, Michael was eager to express himself visually and push

himself to do so in a new way. I was clear as to the main message and areas to address, and the accompaniment of a minor message as further evidence of how he struggles to express himself leaves the door open for discourse as to how his requirements can be met.

Identity and wellbeing

Interpretation 1:



Figure 121: Michael's voice

My interpretation of these images, which arise through the written genre, is that Michael identifies himself as an individual Aspie. That he attaches

'solitary' to this and also mentions withdrawal suggests to me a lack of engagement with an autistic community. He is clearly not comfortable with certain aspects of himself as they have done him no favours, and his labelling of himself as 'insane' is interesting due to the distinct interpretations of this word. As such, 'insane' could suggest a certain eccentricity, foolishness or unreasonableness about his behaviour. An alternative perspective might be that it signifies mental distress. In any event, my belief is that the conflicting messages invite the audience to engage with him and discuss his current lifestyle.

Interpretation 2:

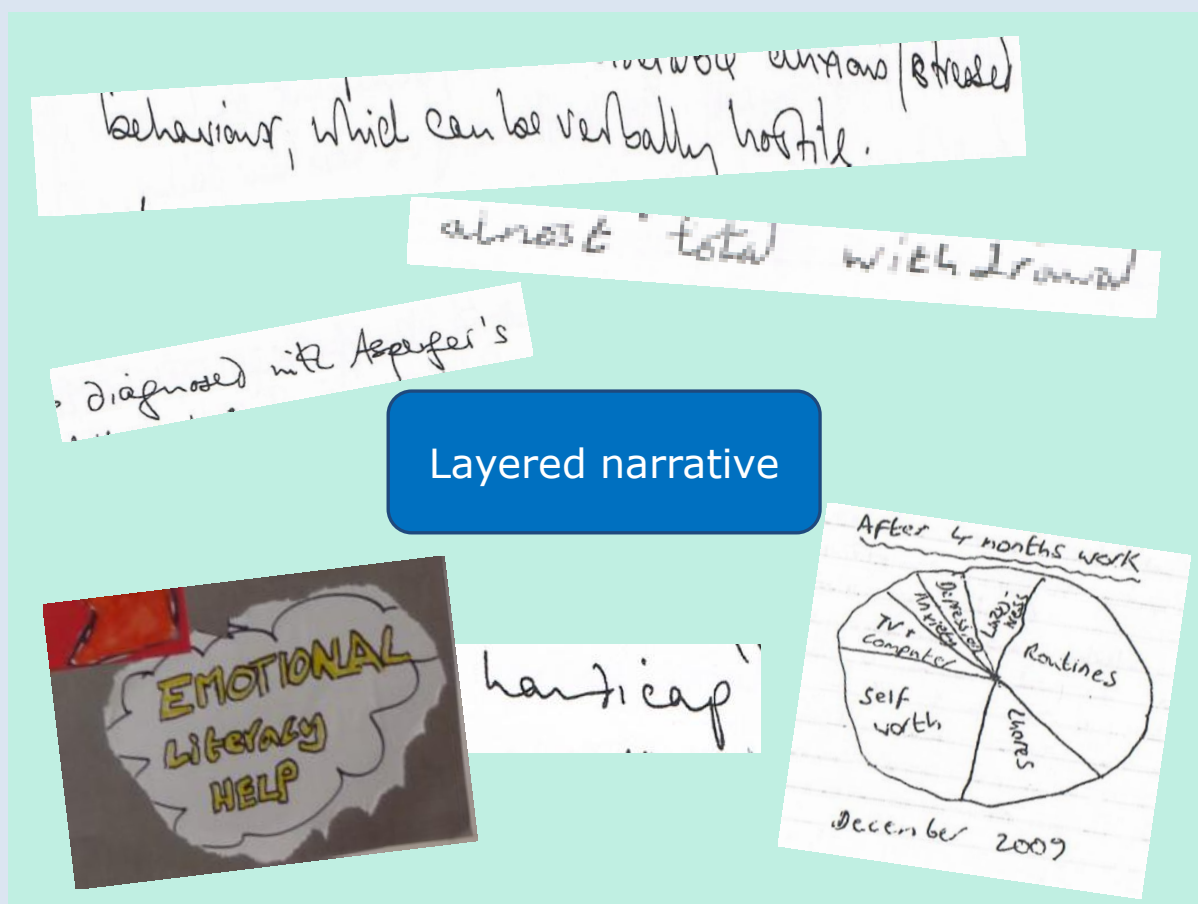


Figure 122: Diverse narratives impacting on an identity

These layers contributing to Michael's narrative include images selected from his mother's written text and his own text and collage. The language used is a mixture of medical model, 'handicap', and terminology that resonate as coming from someone who is engaging in some way with more contemporary language around the expressing of emotions. Consequently, there appears to be a struggle as to the location of power as Michael does not story his behaviour as being verbally hostile, but attends to a narrative inclusive of plots about anxiety, depression and self-worth. As he takes control of his storying, I am able to see an image which demonstrates a shift in his wellbeing, particularly in terms of how he values himself, as he is able to provide structure and meaning to his day. His mother's contribution, nevertheless, does facilitate discussion as to whether Michael would wish to engage with others and how to assist him and work with him to manage experiences of mental distress.

Some of these images indicate that Michael is now beginning to reflect on a difference between past and present feelings and how they impact on his wellbeing. This may have been a negotiated step as a result of discussion with his support worker, and is a critical step in a wellbeing approach. As such this reflection or discussion has facilitated the separation of past bad experiences from the possibility that future experiences may be different.

Context and power

Interpretation 1:

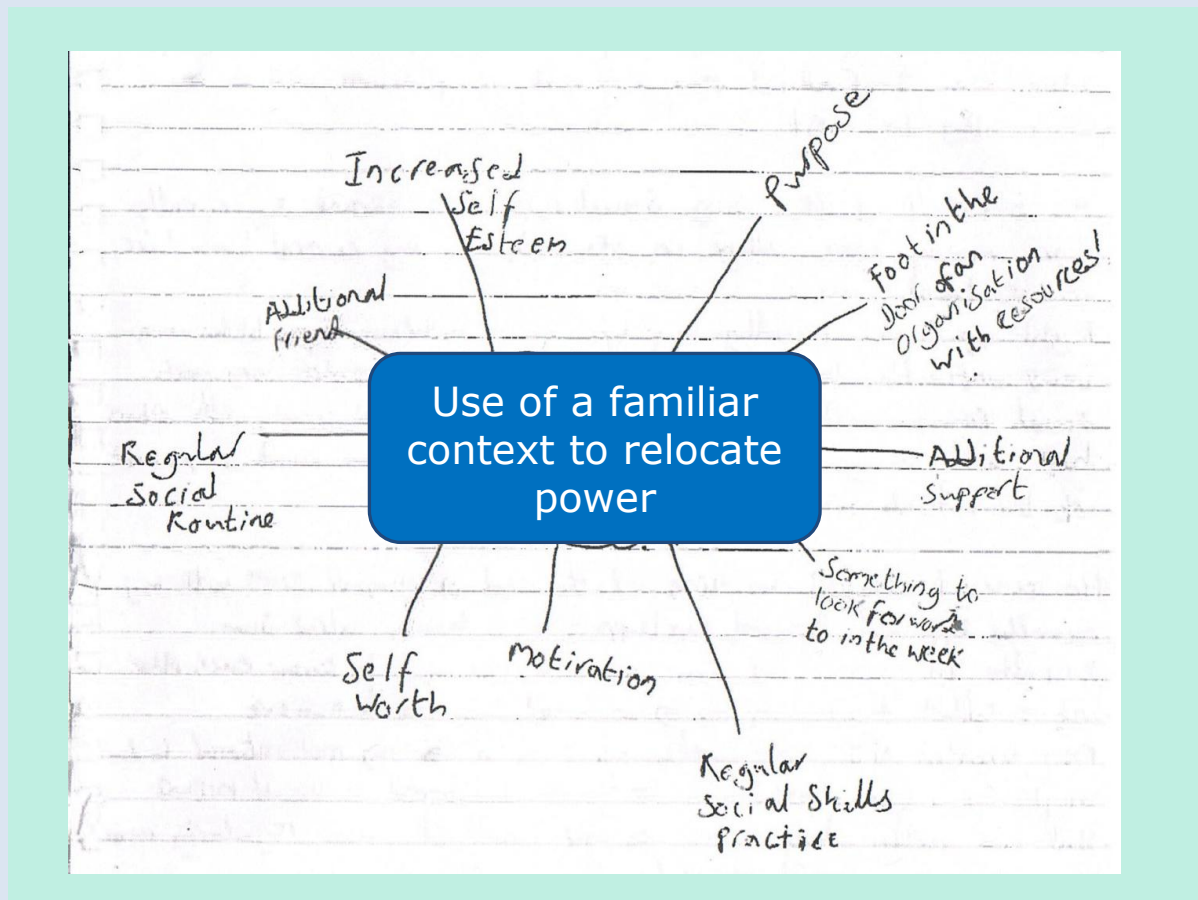


Figure 123: Familiar context

In this particular narrative genre, my impression was that it was Michael's voice that spoke, and, in doing so individually, he relocated power within the process by taking ownership. I am able to see that there is room for continued support to help Michael achieve the lifestyle he wishes and to improve his wellbeing. Importantly, Michael now feels valued and is able to access support in various forms.

The contexts in which this support was provided were forums where Michael felt comfortable, such as his own home and a support group with his mother/support worker alongside. This may have enabled Michael to more easily reflect on his circumstances and to break these down into components, as demonstrated in this narrative. A key element of wellbeing is being able to take control of your life, and this entails managing feelings of being overwhelmed and needing to withdraw. By working in familiar surroundings, Michael is more empowered to story his experiences of support.

Interpretation 2:

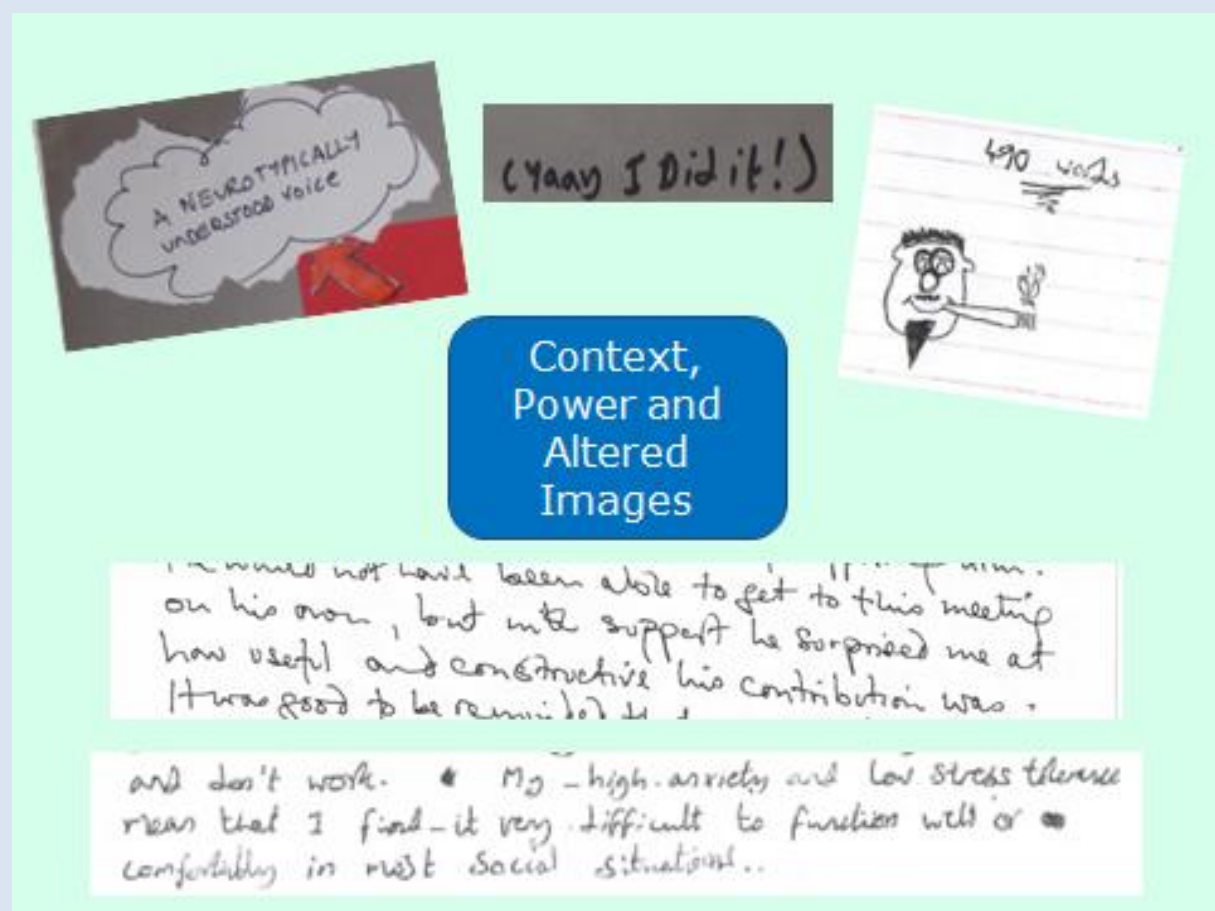


Figure 124: Understanding shifts power

In a setting conducive to listening to his views, and with people alongside Michael, who want to support him and include him in services impacting on him, he is able to seize the opportunity to contribute to a meeting informing the establishment of a support service for autistic adults. The narrative layer offered by his mother indicates that Michael has not been asked to contribute in such a way before, and extracts from Michael's own text suggest that the reason underpinning this might be his high anxiety experienced in social situations. There are indications that he feels happy with his achievement, of which a drawing and a written message are but two, and acknowledging Michael's challenges place him in a better situation to voice his opinions, as he feels valued and the power balance is shifted in his favour.

The narrative genres and layers relating to case study two have been presented and analysed above, and I now present and analyse my third case study.

Narrative case study 3: Peter

Case Study 3

- Peter – a young man accessing a support group



Context

The third case study I present is about Peter, and I chose this particular case study as an example of how a wealth of information can be gleaned from what at first glance appears to be very little. Like Michael, in case study two above, I met Peter at the support service for autistic adults. It is perhaps necessary to re-emphasize that the space was not autistic-friendly in terms of addressing sensory or social overload, and there was no quiet area.

Prior to this session, questionnaires were sent out to autistic individuals inviting them to contribute their voice to the evaluation of the support service provided to them. As responses were anonymous apart from those used in the pilot study with the consent of participants, I had no

information as to how Peter had elected to participate in the collage activity. Nevertheless, there were three likely possibilities: first as a result of selecting it from the evaluation questionnaire as an additional activity to express his views; second, a choice made based on information presented by Social Care staff at a previous support group; or a spontaneous decision made on the night in question.

I only attended one support group session due to a strain on staff resources previously discussed, and as I was dependent on staff to assist me with future contact with him, Peter only engaged in the mind mapping stage of the collage process. However, the process with which he engaged in this session, in addition to the information produced, provided several clues in response to my research questions.

Collage

Mind map process

Although I had brought a range of different art materials with me, Peter seemed unable to move from where he had situated himself, and his movements were very fidgety. As I wondered about the impact of the activity on his immediate wellbeing given the ambient environment, I felt that it might be wiser to select some materials for him so that he did not have to negotiate a busy, noisy and crowded room. As said, I was unsure whether Peter had been introduced to the idea of this activity prior to the session to familiarise him with it, so I placed some flipchart paper and

pens for him to use at his table. I was aware that my moving into his space may have been construed as intrusive, but Peter became less agitated once the materials were in place. The spatial power tension between us resonated with the construction of a shared space.

My impression was that there was a continual shift in power dynamics as we negotiated the task. Undoubtedly I had power at the initial point of selection of the materials used, choosing those used by others who also chose this narrative method, and I was aware that the tools used for narrating would impact on the end result. However, a range was provided, and this decision seemed necessary to facilitate Peter's engagement in the process. Although, provided with a range of colours, crayons and pens, Peter limited himself to a single colour and felt-tip.

Being faced with 'a blank canvas', as it were, to map experiences is a method that I find extremely useful, as this preference for space enables me to stand back and unclutter my thoughts. However, what I had not considered was what a daunting task this may have been (writing thoughts and experiences on a large blank piece of paper) for someone faced with a new activity, and who may be overloaded with different sensory and social experiences. As Peter began to pace more, I was not quite certain where the obstacle lay as regards his engaging with the task. He may have been anxious as to how to begin, experiencing social/sensory and information overload, or even an eagerness to begin, and my presence was preventing this. Therefore, by moving the paper to

one side and placing a piece of A4 on the table, I hoped to reduce the enormity of the task.

Peter required further assistance to begin his narrative to describe and explain his experiences, so I asked him if there were things he liked to do. He told me that he liked playing cricket, and when I asked why this was, he said he liked 'joining in' and the fact that it was 'practical'. I wrote these down, linking them with arrows. Then Peter told me two other things that he liked in response to my question 'Is there anything else that you enjoy?' I also wrote these down for him as he seemed to find it difficult to be close to the table with me there. This process served as a model for the activity I was introducing. I then placed the piece of A4 on the flip chart sheet, thereby enabling Peter to see the information he had already provided, yet still allowing him to have space to shape his mind map in the way he wished. Establishing people's likes and dislikes and their interests opens up possibilities for discourse, and I felt that this decision was a pragmatic step in supporting Peter to voice his experiences. This turned out to be the case.

Image of mind map

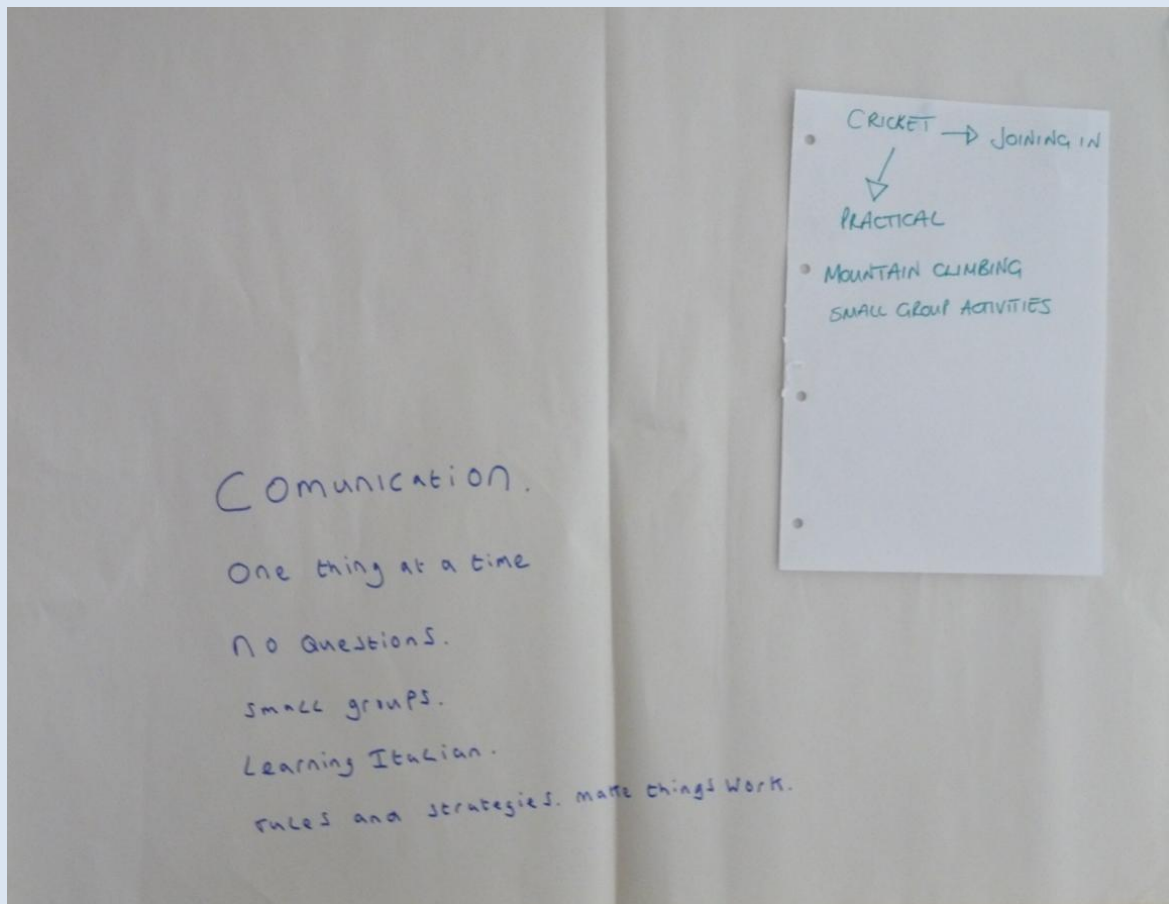


Figure 125: Peter's mind map image

Summary of Peter's collage data

Feelings and thoughts

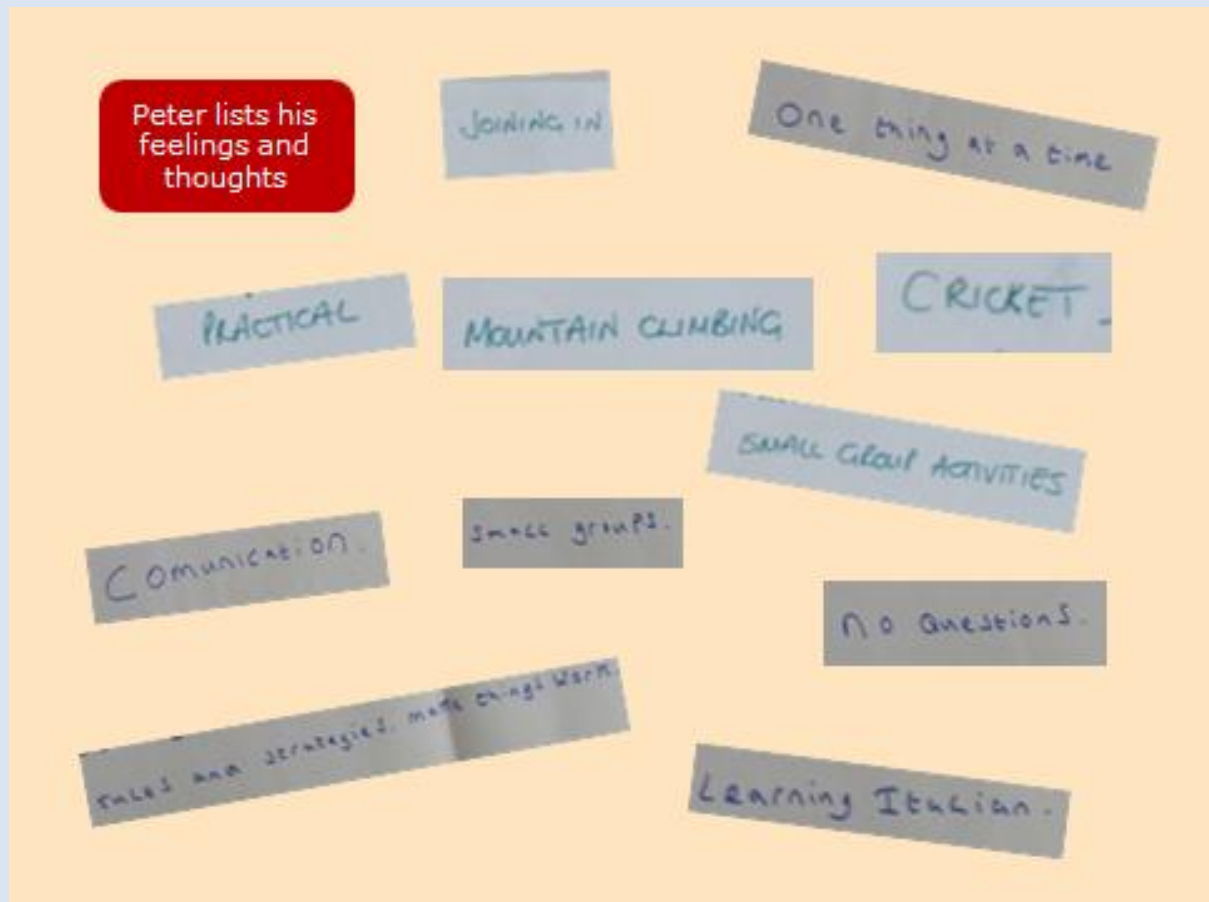


Figure 126: Peter's voiced feelings and thoughts

All the written images might pertain to likes or dislikes, good or bad experiences, yet serve to raise issues which are important to Peter. As such, I am unable to tell whether these are positive or negative experiences or whether they fall into a mixture of categories. Specific activities are mentioned, as are characteristics of groups, yet I am not provided with a reason as to their purpose. However, 'communication' is mentioned, and 'no questions' is possibly an image that is linked to this.

Predominantly, these words serve as an initial list, which as the first part of the collage process could be developed.

Identity and wellbeing

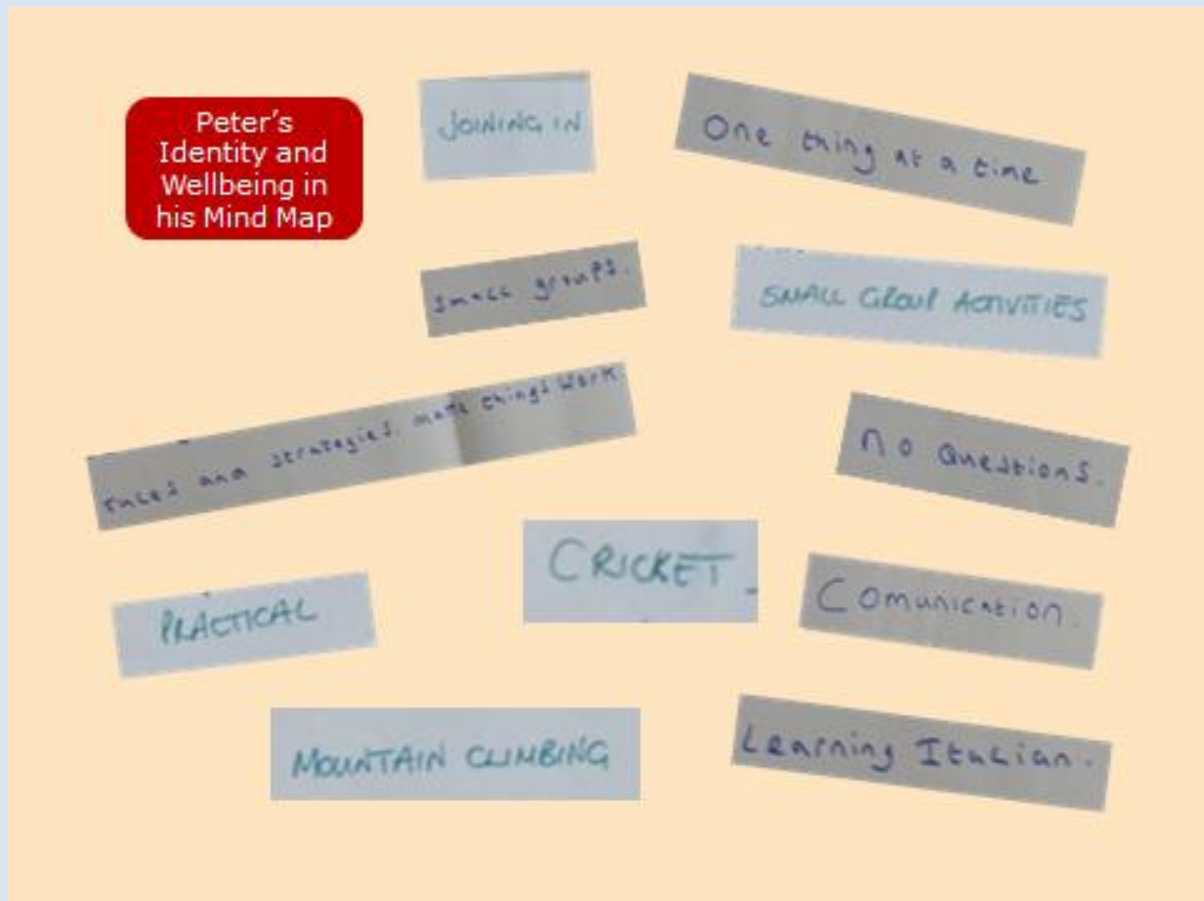


Figure 127: Identity and wellbeing in Peter's mind map

Each image provided by Peter might potentially relate to his identity or wellbeing. The narrative images do not tell us whether these are his likes or dislikes, with the possible exception of 'rules and strategies make things work'. If this latter is linked to other images provided, an identity of a man who may have/has several interests/skills emerges, each of which, contain a quite different structure. In addition, each activity entails 'joining in'.

Alternatively, as I am not told whether joining in is something Peter likes or dislikes, these activities might all be ones where he has experienced difficulties with questions asked, large groups and too much happening at once. Opportunity for discourse is certainly provided immediately by this data as it draws me in to consider the meaning of each, and how or whether they relate to each other.

Context and power



Figure 128: Context and power in Peter's mind map

In the context of the support group, Peter takes the opportunity to emphasize either a like or a dislike for small group activities. Examples of

groups that are generally small are provided, cricket, learning Italian and mountain climbing. However, I do not know whether they are storied for this purpose as each could be an example of different sets of rules and strategies, joining in, one thing at a time, practical activities or ones requiring different types of communication.

In storying his experiences relating to autism, Peter has taken control of his narrative in such a way as to introduce a number of plots which could be linked in several ways. He is the author and correct interpretation requires further engagement with Peter. By drawing me into his narrative in this way, he places himself in a position of power in the authoring of his experiences, revealing the narrative one step at a time. However, this is a power that may need to be negotiated if Peter and I are to communicate effectively about the imagery in this mind map and understand each other.

Researcher analysis

Feelings and thoughts

Interpretation 1:

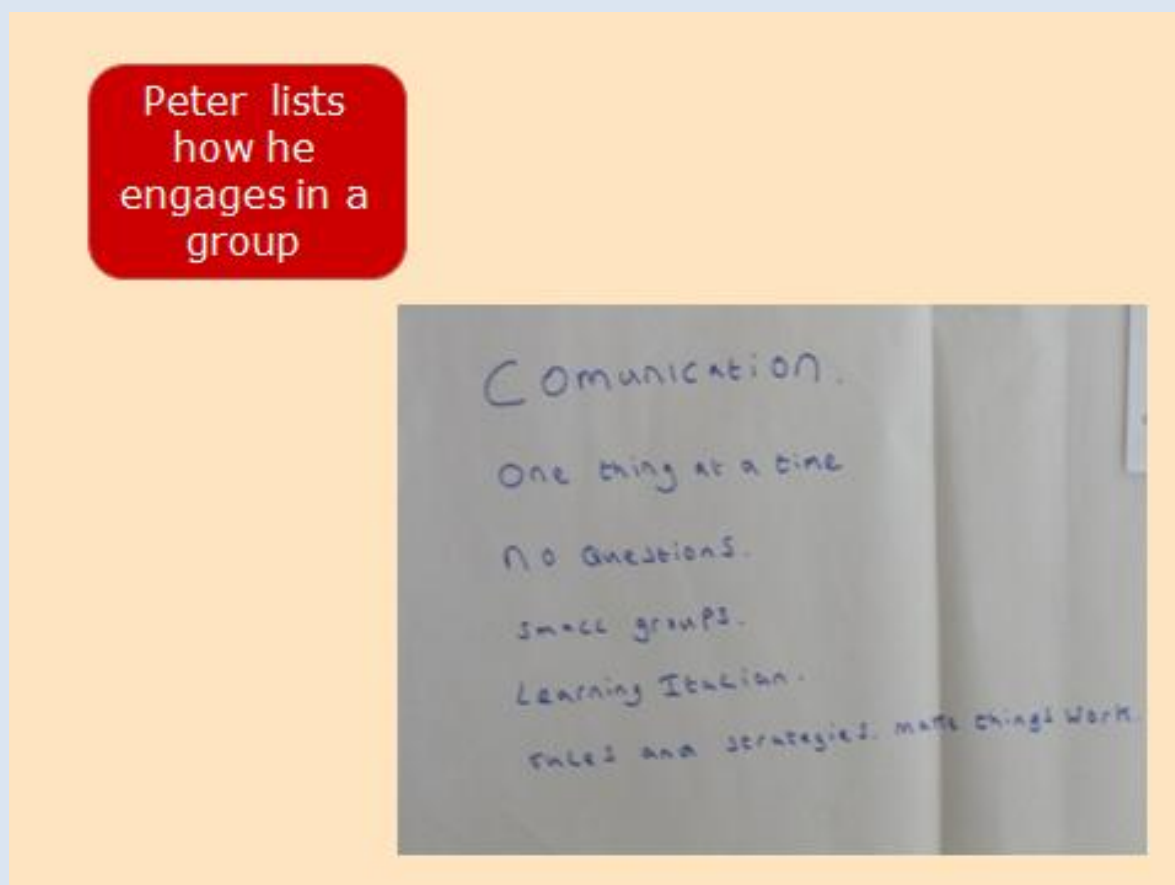


Figure 129: Peter lists a process of engagement

One interpretation of this list produced by Peter was that communication is important to him, and he made use of a list of things which could be applicable to the language learning environment. For example, the presentation of things individually enable him to process things better, and as he finds questions difficult to process and respond to, it is better if

these are avoided. This might well be the case when learning a language in a small group, which has rules and strategies that make things work. As a medium, this initial step has enabled Peter to walk me through aspects that would draw him to certain activities, and I am provided with a wealth of information which would enable me, were I working to support him, to identify activities which embrace his approach to group work. I consider this to be a very powerful way for Peter to state what works for him.

Interpretation 2:

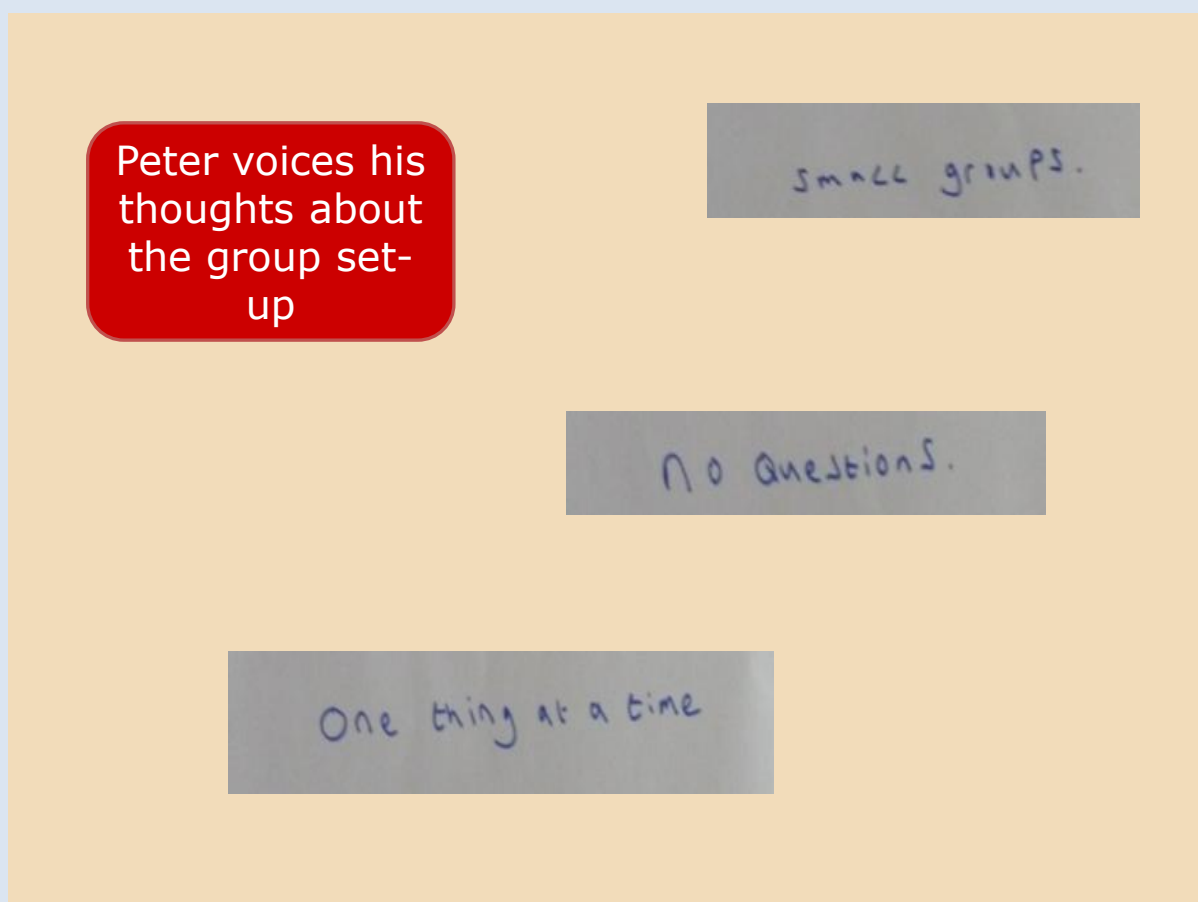


Figure 130: Peter communicates his thoughts about the support group

The visual narrative style seemed to work well for Peter. Reflecting on his list, I was of the view that whilst Peter may have been storying the evening's activity, his list could easily have been applied to other contexts as characteristics of environments which he found enabling. Events that particular night meant that the group was quite large, around thirty people present, and with two concurrent activities, there was a considerable amount of noise and chatter. Both of these may have been uncomfortable and challenging for Peter to deal with, so his story could be interpreted as future desires to join in activities in a more structured environment. As such, this could be a stepped approach to Peter developing his skill base, and if applied to wider situations could remove barriers to him contributing to society.

Identity and wellbeing

Interpretation 1:

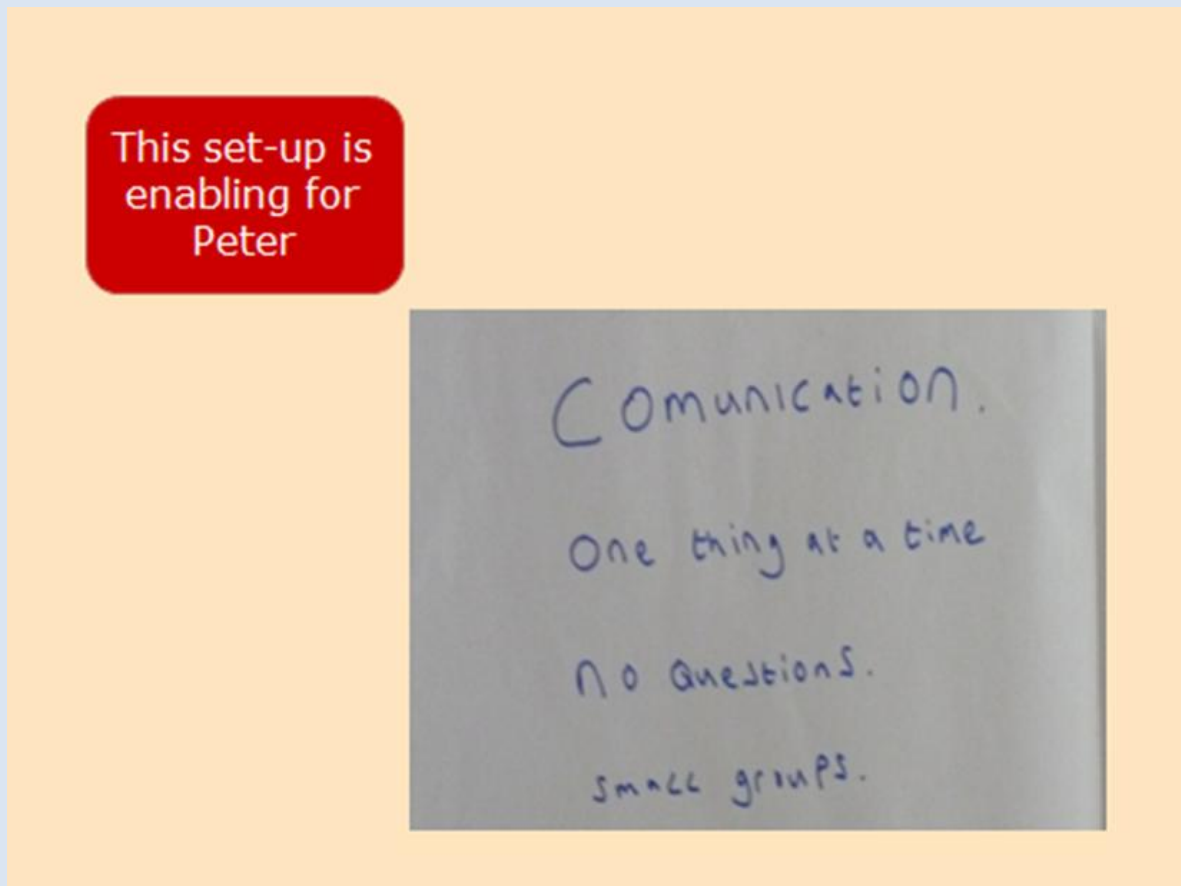


Figure 131: An enabling environment for Peter

The context storied Peter's wellbeing, and demonstrated the impact of large groups on him. It was clear from his behaviour, pacing around, that a large noisy group made him extremely anxious and was extremely disabling for him. However, despite his feelings in that particular context, he was able to story characteristics of an environment that had a more positive impact on his wellbeing.

Questions were particularly disabling for Peter, and they may have overwhelmed him leaving him excluded and disenfranchised – the antithesis of what support workers might want to achieve in trying to include him in this way.

Interpretation 2:



Figure 132: Certain types of groups work well

Contrary to what his behaviour that night would suggest, as an individual, Peter's expressed interests lay with activities that required team work and the further development of diverse communication skills. The activities named require distinct verbal, non-verbal and physical skills.

As a language, Italian hails from a culture where words are frequently accompanied by physical gestures to add emphasis, and where statements are made more use of than in the English language, as in 'Give me a pen' instead of 'Can you give me a pen, please?' So this reflects his identity as someone who engages better perhaps with statements as they are clearer and require less processing.

Cricket demands the establishing of 'a team spirit' and both collective and individual goals, as in winning or gaining the best individual score for an innings. As such, Peter can push himself to work to both of these, and in so doing establishes himself as an individual with a potential friendship community.

The demands of mountain climbing are interesting to me in a different way due to the skill set they tap into. There is a huge element of trust required and an eye for detail and precision. In addition, being able to respond quickly and appropriately to instructions is a key element embedded in the sport, and if given as instructions is probably a feature of this activity that Peter would engage with well.

Context and power

Interpretation 1:

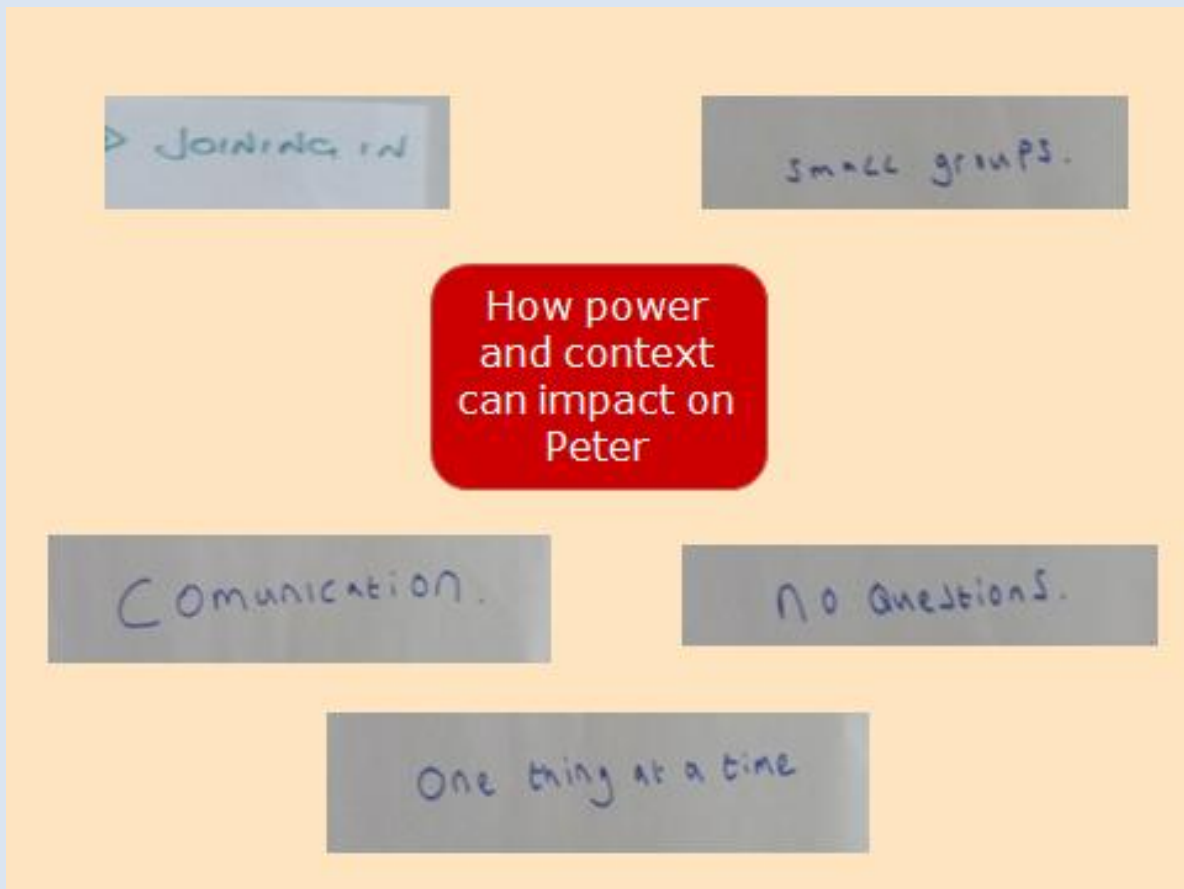


Figure 133: The impact of power and context on Peter

At first glance, images from Peter's mind map seem to tell me very little, and especially when compared to information yielded by the previous case studies with their range of narrative layers. However, Peter's narrative provided me with an example of the importance of contextualising experience as it adds a depth of information otherwise lacking.

My immediate concerns when I met him were around who had accompanied him, as there was no support being offered to him to

engage with the activity in the way that others present experienced. This complete handing over of power to him to control if and how he took part in the collage, seemed to me to be completely disabling as an experience with a considerable negative impact on his wellbeing. Secondly, his use of space indicated to me that either he considered others to have a more powerful ownership of the room, which left him feeling overwhelmed and disempowered, or that in feeling this location of power, he was somehow enabled to claim possession of an area which he marked out for himself by pacing around. His storied components pointed to an experience that night, which was almost certainly inhibiting his engagement and the voicing of his experiences.

Interpretation 2:

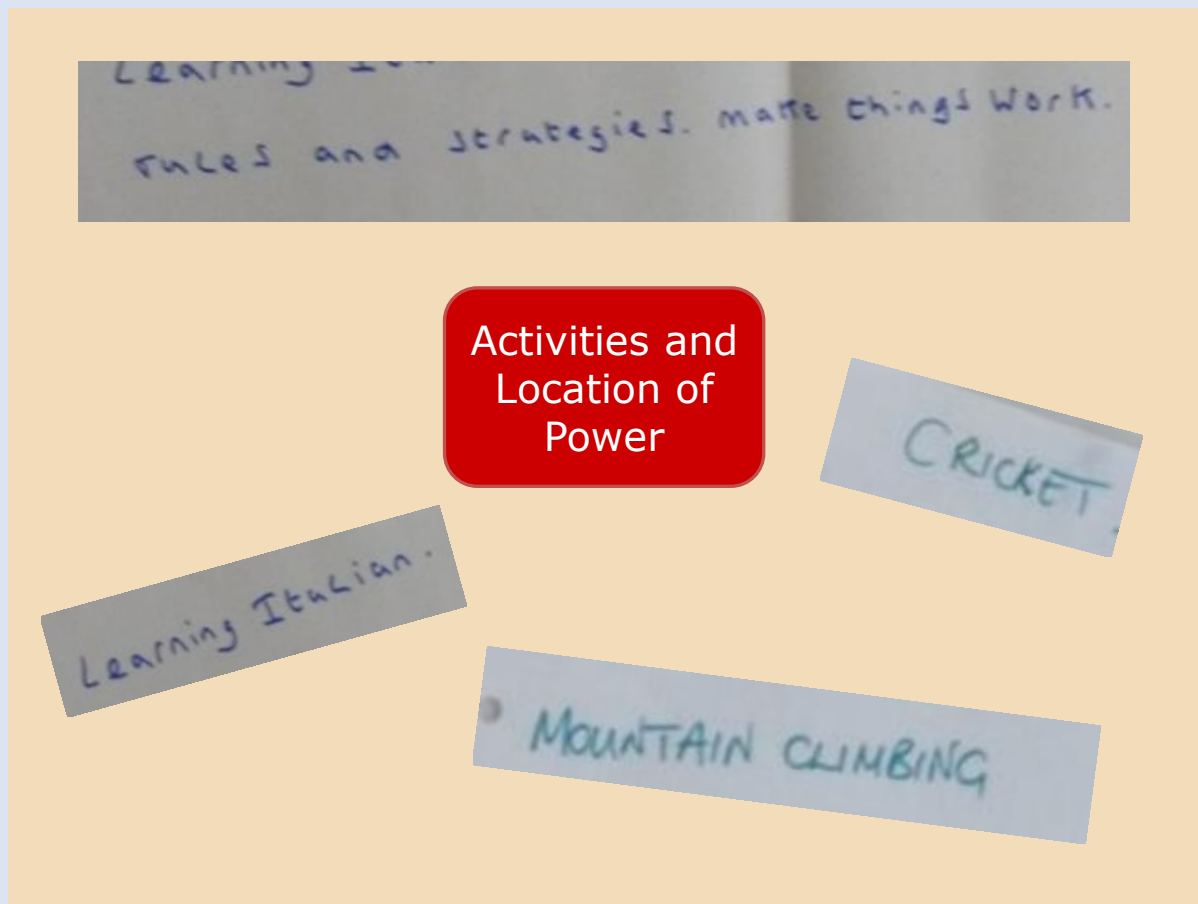


Figure 134: Location of power

Another of my interpretations of how power was situated within the context of the support group was to consider Peter's storied list, which spoke to me in terms of my presentation of the workshop. Perhaps I needed to simplify and clarify my instructions, and as I had asked questions to elicit responses from Peter, it was important for him to inform me that he really did not like this approach. So inadvertently, I had adopted a 'power over' stance by asking too many questions, and perhaps there was insufficient time that night for Peter to process and voice his thoughts, feelings and ideas.

Peter has several interests, and I was unsure as to whether he did any of these at that time. Each of these activities above allows an instructor to demonstrate a task or verbally explain it without a need to ask questions, and this was the way in which Peter had been able to take part in the mind map activity on the night we met. This provides a clear steer as to Peter's strengths and ways to include him.

Summary

I have used my research question to present my findings for my three individual case studies, and each has an accompanying researcher analysis providing some possible interpretations of the data. The next section is a meta analysis of my data, which presents a bigger picture of autism provided by these narratives by weaving together the themes raised. This is a critical step in my study, as I believe that evidence reviewed in Chapter 2 indicates that the presentation of a broad picture generally irons out the individual voices often decontextualising experiences. This does not have to be the case.

Chapter 6: Meta Analysis of Case Study Findings

6.1 Introduction

In this chapter I present my data as a meta analysis, reflecting on and weaving together collective themes raised by the individual case studies discussed in the previous chapter. As with the analysis of my individual case studies, this meta-analysis addresses my research questions, placing findings within my theoretical and analytical framework blending IPA, narrative analysis and CDA. In addition, I again made use of the four key sites of meaning making (process, image, audiencing and turning points, each with discourse throughout) to make sense of the experiences of autistic people from diverse perspectives and as addressed by my research questions.

Using this approach, I aim to maintain the clarity and presence of each individual voice. My data analysis is innovative in the field of autism in that it focuses on material used and the sites of meaning making. This differs from a historical focus on images that are 'found', such as photographic records of events and archived material (Riessman, 2008, p171).

6.2 Meta Analysis of Case Studies

There are three main areas that I attend to, as raised by my research questions, and in drawing together themes from the individual case studies I have chosen six key stories that stood out to me within each as an audience to these collective images.

Theme 1: Feelings and thoughts

Telling new stories: a non-linear approach

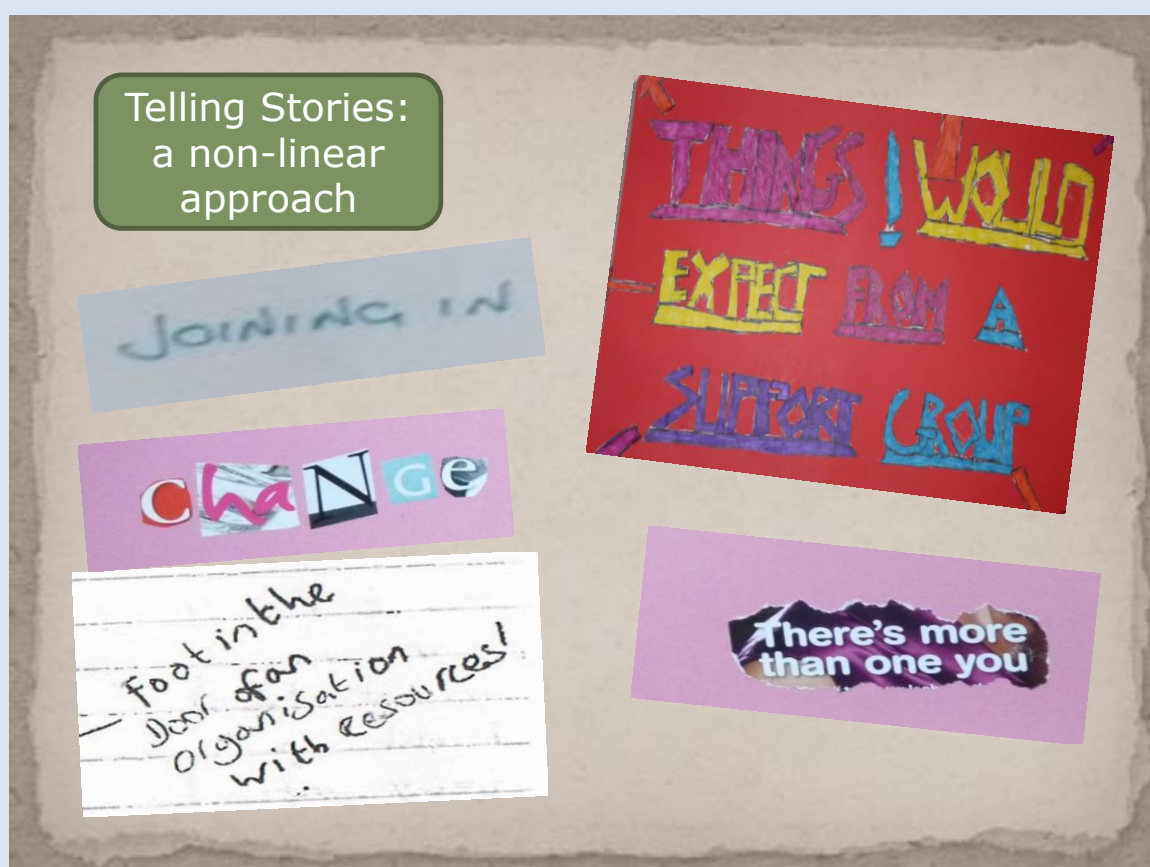


Figure 135: Telling stories – a non-linear approach

Mixed expressive media enabled autistic individuals to introduce and prioritise their stories and themes, so introducing new stories. This non-

linear approach assisted each storyteller to voice their thoughts and feelings about their experiences (Vaughan, 2005). As a more creative process, it allowed each to dip into a pool of memories and experiences which they wished to story, thereby providing layers to this wider picture (Luttrell, 2003; Riessman, 2003). Furthermore, the media used allowed me to see how the description and explanation of their similar yet distinct experiences had also embraced themes of anxiety and exclusion, and where issues such as change, expectations and inclusion might be able to transform their real life experiences.

The diversity of the narratives regarding thoughts and feelings is critical as it embraces the individuality of autistic people within the broader autism narrative, and dispels the myth of autistic people as a homogenous group (Reeve, 2002). Rather, these narratives took advantage of the diverse genres, which introduced a more realistic flavour to the experiences of autistic people that strikes a chord with me and is reminiscent of the narratives of many of my family and friends. Images I have selected point to the storying of a similar theme suggesting dissatisfaction with things as they are and expectations which might feed into change, perhaps tapping into different identities and membership groups.

Constructing and deconstructing narratives

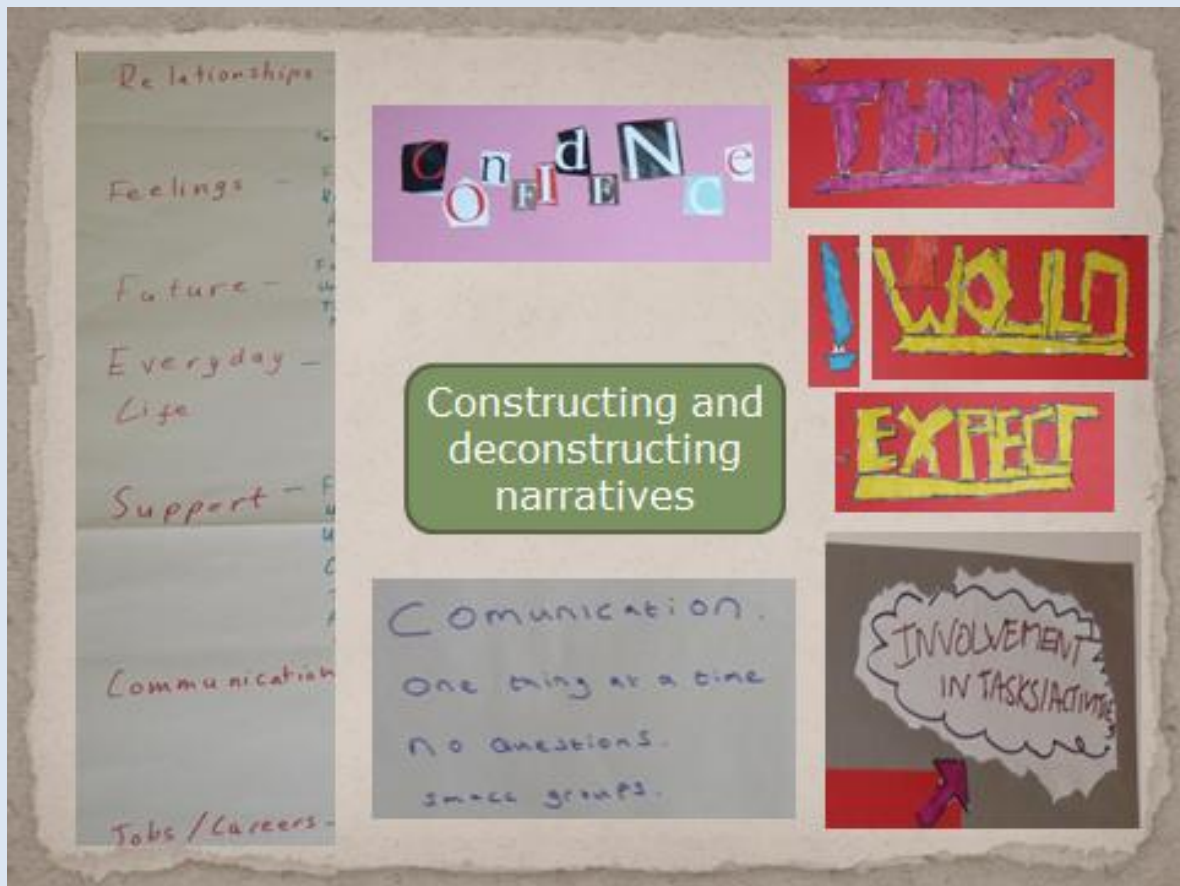


Figure 136: Constructing and deconstructing narratives

A second theme that emerged, as illustrated by these images, was that working between genres, and also with the mindmap alone, enabled participants to organise and re-organise their images, and this is a factor that Grandin (2009) states is critical for visual thinkers. The collage process enabled them to select and adapt media at will, using pieces, such as selected words or phrases, or to construct words using letters, images and crayons to identify and convey a clear message(s). Interesting to me was that the list produced by Peter (as a first step towards a collage) was one where he narrates himself in a context where

the conditions of storytelling have a direct impact on what was storied (Holstein and Gubrium, 2000). This is a key point for those endeavouring to engage with the narratives of different authors.

Narratives across data sets



Figure 137: Misunderstood and not heard

The complex and multi-layered stories produced using different combinations of narrative genres permitted participants to use media as it was, or to distort the image so that it provided their own representation of their lived experience (Awan, 2007; Kostera, 2010). As I mentioned in my literature review, it has been suggested that we are educating people

out of their innate creative flair (Robinson, 2006a). Nevertheless, the authors demonstrated to me, that when presented with different narrative genres, their imagination comes to the fore and enables them to access a storyline that may previously have been difficult to tell (Mischler, 1999). The evidence for this is that in the cases of Sophie and Michael, mixed expressive media enabled them to describe and explain challenging experiences, and open up potential for discourse to assist in the transformation of their experiences in the way they would wish. Peter was also able to describe and explain his experiences, though in words. The depth of information provided in his text was essential for me to understand the context, content and possible meaning behind what he was saying (Harper, 2002), and I considered Peter's text as tempting interaction and discourse with interested parties to help him transform these into positive experiences where he felt valued and fulfilled.

The images selected demonstrate the depth provided to the narrative of autism as layered explanations are offered by each data set, and there is a potentially greater availability of points accessible to an audience to clarify meanings. In a practical sense, this means that service providers are afforded greater opportunity to engage with autistic individuals to discuss their support requirements. However, that there are plenty of autistic narratives does not, as I have said, mean that they have been listened to or acted on (Milton and Bracher, 2013), so this increased

provision for meaningful engagement can only be welcomed if resulting in improved outcomes for autistic people.

Diverse terminology

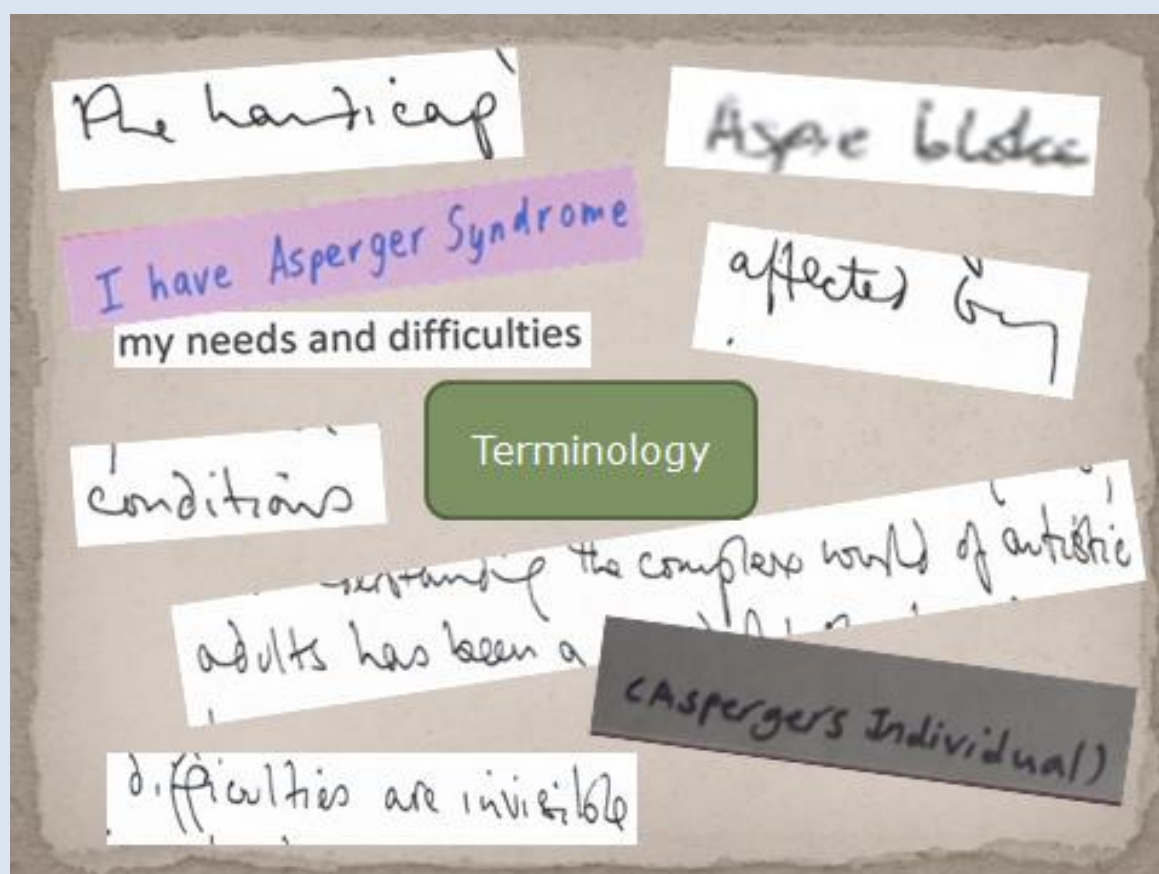


Figure 138: Terminology

The storyline introduced by these images is confusing unless the audience is aware as to the location of the autistic voice. The construction of a broader picture of experiences of autism occurred by the introduction of different narrative layers also including the perspectives of parents and support workers. In the case of the narrative texts, my feeling was that a storyline was constructed jointly at times, but that with Sophie's in

particular, this may have marked a boundary to her narrative which she chose to push through by using the collage.

The contribution of IPA in interpreting this narrative is that the different layers added by non-autistic others made use of terminology which was at variance to that used by autistic participants working on their own. The former did not acknowledge the social construction of 'a normal brain' (Walker, 2014) and the natural existence of neurodiversity. This discrepancy between the favoured terminology of autistic participants may have reflected a certain group membership characterised by ownership (Sinclair, 2007), preference (Larkin et al., 2006; Smith, 2004) or repetition of imposed identities (Bornstein, 2013; Rockquemore and Brunsma, 2002; Sequenzia, 2012), but discourse did not take us into this domain to pursue this matter.

Location and clarification of voice



Figure 139: Different narratives introduced by different layers

In selecting these images, I wished to illustrate a point embedded in my first research question, namely knowing whose story is being told. As each individual engaged differently in the narrative genres and processes, so too did others involved with their support be it family or Social Care. The use of mixed expressive media provided opportunity for me as an audience to question whose story was being told and whether the dominant narrative, therefore, was that of the individual or some other person (Andrews, 2002a). The narrative layers added by the two mothers involved storied anxiety relating to concerns about the future

independence of their family member and a sense of being overwhelmed. However, the narratives of Sophie, Michael and Peter gave greater insight to more immediate concerns.

Two examples of these discrepancies were apparent. First, the collage process between Sophie and her mother demonstrated where two possibly distinct narratives were converging, and where themes were later simplified and re-prioritised by Sophie. A second example is when Sally's parental narrative places more emphasis on the past and the future when she and Michael's father are not around to support him. However, Michael uses the creative media to show a preference for storying his current support requirements, and in so doing, his views are unambiguous and independent.

The future



Figure 140: Voicing feelings and thoughts

The future story authored by autistic authors is more subtle and tentative than the future narrative told by parents, with precedence being given to past and present themes. Sophie did not detail her future other than that it would be 'a good future'. Nevertheless, there were plots throughout her narrative that point to issues impacting on her future, such as romance, love and friends. Michael's approach to storying his future contrasts as he provides detail as to the format of helpful support using his narrative text and accompanying pie-charts to indicate fields which he finds useful, and which would impact positively on his future. This is an issue frequently raised by autistic authors (Dunn, 2014b; Isaacs, 2014a; Lawson, 2015).

His collage is more specific about the set-up of a support group. My interpretation of Peter's story was that the future was possibly embedded in his narrative; however, he did not specifically state whether themes mentioned related to past, present or future themes. Although themes seemed different across all three case studies, similarities and differences existed which continued the theme of individuality within a broader narrative.

The images selected place emphasis on the various experiences of social expectations regarding fitting into a normative agenda, including the parental experiences. Sophie's textual narrative of how relevant support helped her to develop skills in independent travel to access a new activity ran concurrent with the theme of high anxiety later pursued in the collage. This interwove with a different storying of anxiety as told by Michael, drawing a comparison between his past and present with and without support, and his storying of a useful support group also had anxiety embedded in its production. Peter, on the other hand, spoke to anxiety using a performative narrative by using dramatic rhythmic movements perhaps as a result of an unfriendly ambient environment; nevertheless, he maintained control of his wish to voice his thoughts. So the building of a more complex range of experiences occurred, and in interpreting the images, an acknowledgement of diversity was critical in the recognition of each individual's experience within a more expansive picture.

An interesting gap involved the production of an image which is both visual and performative, which would escape the notice of those not audience to this. In authoring the process, therefore, I became aware that this image was in danger of becoming 'missing data'. Taking an approach that enabled me to 'listen' to silence better, I was able to see that it was, in fact, not neutral or empty (Lewis, 2010). Rather, in watching Peter, I was able to reflect on his movements and respond to these differently. In addition, the narrative analysis feature of my theoretical framework allowed me to acknowledge this data, and so Peter's storyline could be incorporated, which gave me a more robust understanding of the impact of his experiences. Across the narratives, there was a combination of both distress and enjoyment, which plotted a certain tenacity to be heard and to participate, and a frustration at being excluded, particularly from so many environments whose adaptation to suit autistic people would address the comfort of a more neurodiverse population (Silberman, 2015b, p472).

Theme 2: Identity and wellbeing

Fluid identities and hedonic wellbeing



Figure 141: Identities

My interpretation of the wider story emerging from these images is one of fluid identities, which could attend to a theme of hedonic wellbeing. There is an incomplete story of active involvement as the terminology used indicates a sense of 'being autistic', of somehow being different and experiencing exclusion, and this is supported by statements asking for support and recognition of diverse identities. However, the images imply that all three saw themselves as 'more than autistic'; as individuals with interests, and whose concerns fit with the narratives reviewed in Chapter

2 around wellbeing (Murray, 2006a), wanting to participate (Ne'eman, 2010), recognition of diverse identities (Lawson, 2006a) and barriers to this (Brook, 2014; Isaacs, 2014b). As such, their identities related very much to their present and current requirements. This stands in stark contrast to the normative agenda, which is very often a linear tale, addressing themes of future prospects around further education, employment, independent living, maybe a relationship and a family (Valentine, 2010).

It can be argued aaathat the collage images represent an identity through difference (Tajfel and Turner, 1979). In terms of hedonic wellbeing, this can also be defined as an 'ingroup' versus an 'outgroup' image, namely autistic/Asperger syndrome versus neurotypical. This is an issue also addressed in a similar argument regarding 'the distinction between equality and sameness' (Appiah, 2000). In using the 'equality of sameness' as a defining factor of either 'in group' or 'outgroup' membership, what I noticed is that this has resulted in what Appiah describes as 'an ideal of equality in counter-reaction to this'. However, this equality is only evident if the methods and contexts that are available for us to story our experiences are accessible to us.

Essentially, the images focus on how, in adopting a specific identity to provide ourselves with a sense of agency, we place ourselves in a narrower category than if we were 'equal outgroupers' (a term I use to reflect those seen to be treated equally in terms of power, yet who fall

outside the identified group of individuals with a diagnosis of Asperger syndrome). Whilst both Sophie and Michael identify themselves as having Asperger syndrome, Michael clarifies the issue of an 'outgroup' further by specifically stating that the 'outgroup' he is referring to relates to neurotypicals (NTs). There is a dimension here that warrants further exploration, namely the embedded implication that both autistic and NT groups are somewhat homogenous. It is uncertain whether Michael actually considers this to be the case, or whether an underlying issue such as past and present social opportunities might have led him to consider these social groups in terms of 'those who cause me anxiety' against 'those with whom I feel comfortable'. My findings highlight that a range of methods, in particular ones combining visual and discursive elements, would be well-suited to exploring this issue further. Peter's story runs along a different plot speaking to activities and interests, which would also point to a sense of belonging and hedonic wellbeing. Therefore, these varied narratives are important to listen to as each can provoke dialogue and engagement with other authors.

The diverse media used demonstrate the potential for unearthing and exploring a wider range of identities than those perhaps more immediately presented in narratives by autistic authors, their family members, their support workers or researchers engaging with them. Given the fluid nature of identity, the images produced for my study in this short space of time suggest to me that the more opportunities

autistics are given to voice their opinions, the more identities that will be shared or constructed.

Imposition of identities

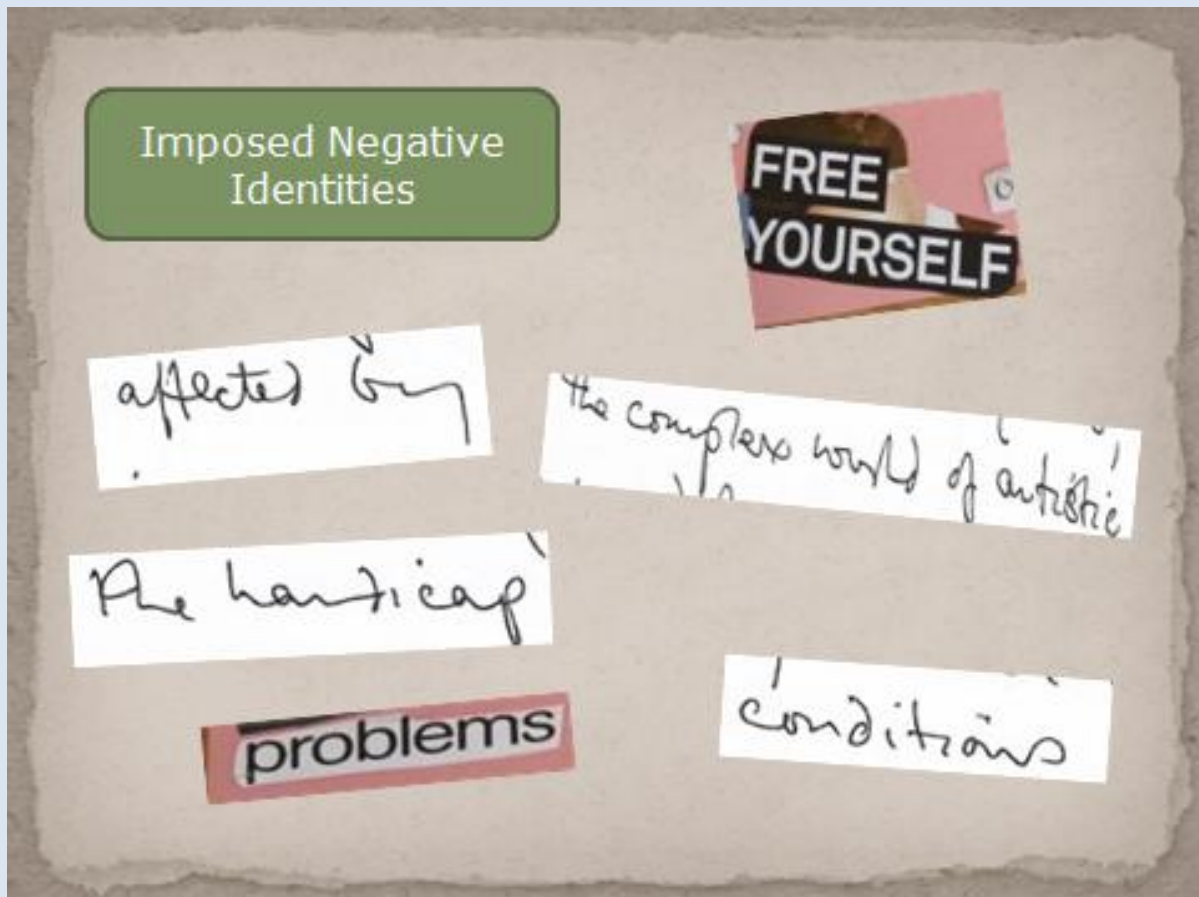


Figure 142: Imposed negative identities

My reason for selecting these images is that they ring with medical model terminology, suggesting: that autism is an appendage; that somehow one can 'escape' autism should one choose to; and a curative plot that would seek to address a dysfunctional human. It is a narrative which makes me feel extremely uncomfortable, yet it is one to which, as a neurodivergent person, I am frequently exposed. For this reason, it makes me reflect on

the prevalence of this type of discourse in the lives of the autistic authors in my study.

The terminology used does not indicate to me that it is the non-autistic author's terminology, and I am more than aware of the frequent imposition of debilitating medical model terminology on both individuals and families that places the autistic individual in a setting which is 'outside of normal'. The impact of these images is extremely powerful, since if these are the only ones seen, the skewed image of autistics is the presenting one that would continue their exclusion from any meaningful contribution to society. Furthermore, it would perpetuate the social barriers already in existence. For this reason, it is fundamental that the messages conveyed by the images representing the autistic voices are listened to.

Social influences



Figure 143: Social influences

Included in the narratives of individual authors were images pertaining to social influences, which I have presented above. My interpretation of this story is that there is a collective sense of 'othering' of neurotypical individuals, who may be family, friends, or members of interest groups, who are in a position to provide comfort and understanding and could facilitate a process of inclusion. Yet this othering suggests a narrative of the experience of autism, which requires an explanation as to 'what makes things work', what it is about a specific activity or social situation that would satisfy an individual or enable them to function as they would wish by attending to their wellbeing.

Collectively, plots around friendships, NT understanding, and joining in indicate a mutual desire, and the implications for wellbeing are that this needs to be heard in order not to render individuals powerless. Their identity shell of autistic, is rendered unsafe should NT others not wish to engage in a manner which is inclusive and acknowledges their diverse individual and collective support requirements.

Interests

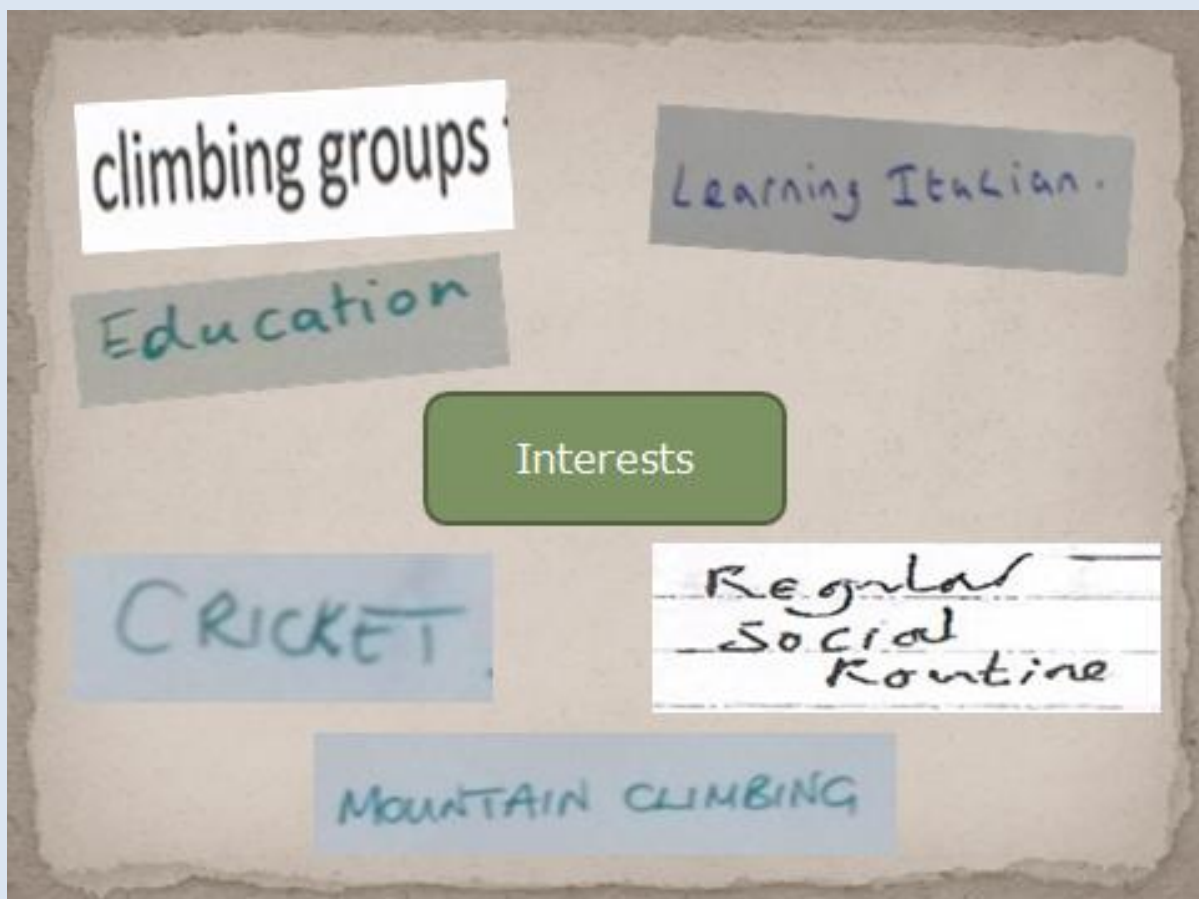


Figure 144: Interests

The collective images spoke to a theme of existing interests or a wish to develop these. Each of these activities or interests required a distinct skill

set, and one which necessitated engagement with others on various levels. The detail provided by this selection is interesting to me and critical for service providers as it indicates that these autistic individuals wish to have an active lifestyle with opportunities for meeting others (Autescape, 2013; 2014; NAS and Ask Autism, 2014)

This narrative theme runs counter to the dominant narrative in literature, which suggests that autistic people prefer a quiet, almost solitary existence (Attwood, 2006; Barratt, 2006; Lawson, 2006b; Sainsbury, 2009). This may characterise their present day experiences, however, in the light of this storyline above, discussion is warranted as to the origin of the more isolated and solitary lifestyle of each author and the possible changes to address this.

Each activity chosen had a certain embedded predictability, with perhaps implicit and explicit rules and strategies. Yet each was available to develop and provide a challenge to any participating individual, indicating that each author wished to grow and develop as an individual, building on their knowledge and skill set.

Enabling environments

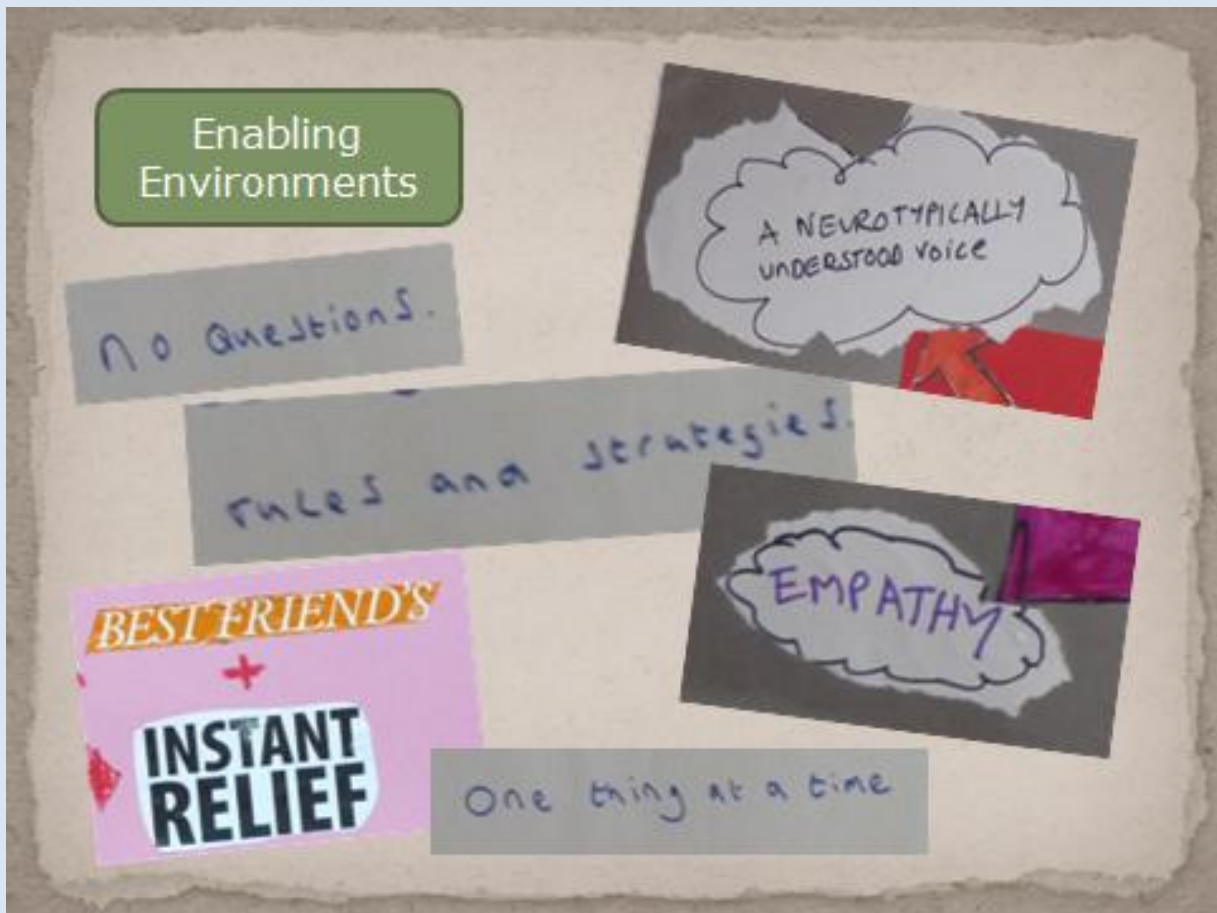


Figure 145: Enabling environments

The theme storied by selected images above speaks to both the identities and wellbeing of authors concerned. The impact of the different settings where narratives were storied had a profound impact on both the narrators and me as audience, and was a theme that each chose to story. Some of the narratives took place in a context where the non-autistic author may have felt more in control, such as their home setting. However, this may not necessarily have been the case, as many autistic people feel that parental narratives take precedence in certain settings, and the home may be one of these (Yergeau, 2010). Given this potential

power shift from disabling to enabling environment, authors' stories were more around 'what works for me', with the assumption being that the opposite would be disabling and would act as a barrier to activities that individuals wished to engage in.

Should the messages in this narrative be attended to, the autistic authors would be more able to participate. However, the flip side of the images in this collective narrative highlights areas which might provoke anxiety, and this is linked to autism-unfriendly environments and a lack of understanding. It is likely that these impact negatively on the development of diverse skill sets and participatory interests as represented by features of their expressed identities. This picture challenges assumptions made, which suggest that autistic people do not wish to join in. Rather they point to social barriers, and in so doing, illustrate the complex web of issues impacting on identities and wellbeing. This required more time to allow in-depth exploration.

Eudaemonic wellbeing



Figure 146: Eudaemonic wellbeing

The images presented here show a mixed story of autistic experiences and wellbeing. Eudaemonic wellbeing concerns living well, having a sense of purpose in life, being able to exercise agency and choice, and also the opportunity to build relationships (Glasby and Beresford, 2006; Glasby and Tew, 2015). As discussed in Chapter 2, this aspect of wellbeing is frequently reduced among autistic people due to social barriers to accessing activities and engaging with others (Brown, 2008; Garvey, 2008). However, the fact that different environments are being accessed

such as chat rooms (Brownlow et al., 2006), suggests opportunity to develop collective ideas and movements to tackle some of these barriers.

That one of the authors was provided with 'a couple of choices' regarding an activity is not indicative of a sense of agency, rather it could suggest a more controlling approach, which impacts negatively on her wellbeing by limiting opportunities. However, there is a sense of agency in the phrase 'Aspie bloke', and possibly in the phrase 'I have Asperger syndrome', although it is difficult to determine the location of the autistic voice due to the choice of person first language. Nevertheless, there is a sense of agreement that support and understanding are required, and suggestions are made by way of response.

Theme 3: Context and power

Autistic voice to the fore

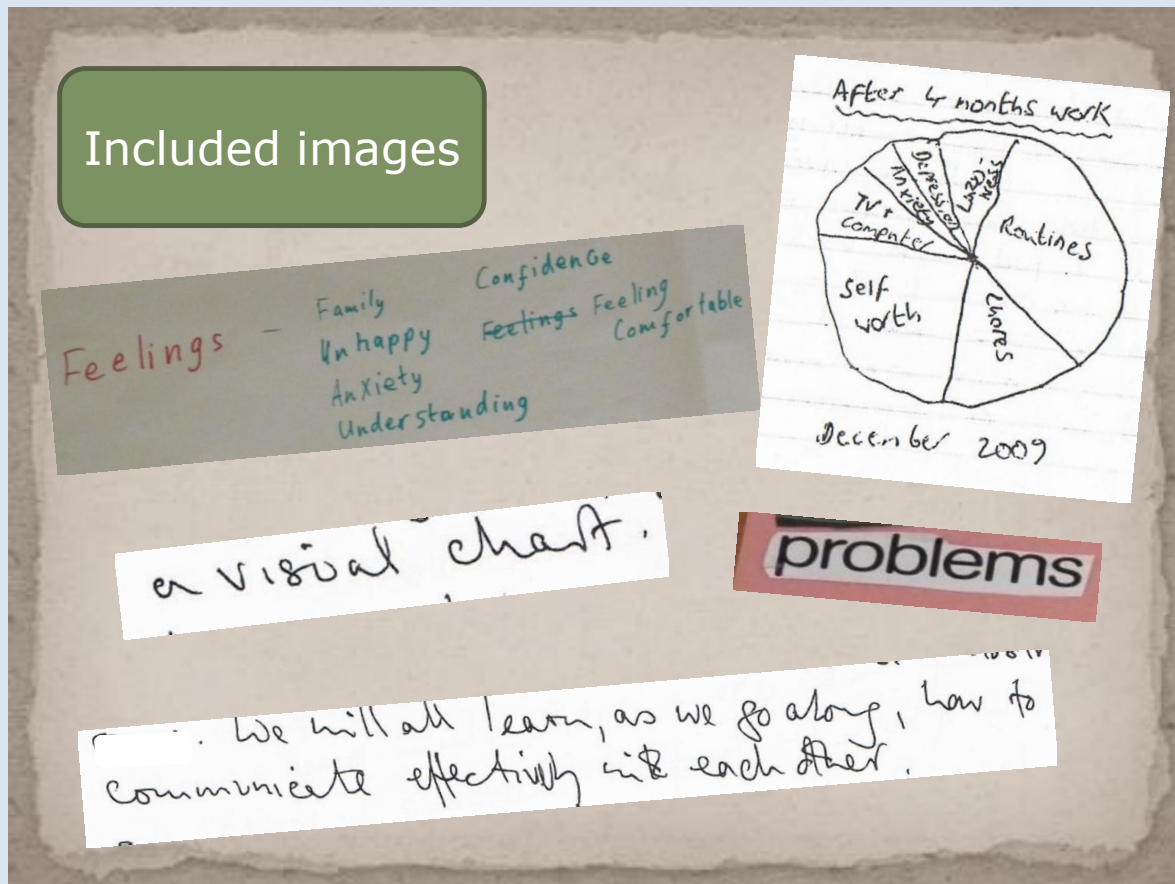


Figure 147: Autistic voice to the fore – included images

The location of the autistic voice to the fore allowed participants to shift their narrative images to the present and more immediate future tenses. The images I have included from the parents' narratives also seemed to resonate with the autistic authors. Collectively, authors produced an image which storied current feelings of unhappiness, yet provided a sense of how quickly this could be turned around with support. A wish to express problems visually and address them practically required being

listened to, understood and supported in order to establish a way to explore effective communication.

This was expressed as a journey of discovery, which addressed one of the paradoxes of this study, namely that many autistic and NT individuals argue that they have difficulties communicating with 'the others'. This dilemma, described as the double empathy problem (Milton, 2012a), is one where the oppressive influences of social hierarchies have led to the current situation, whereby autistic people are being 'groomed' to fit an NT world. The images informing this collective narrative play a critical role in emphasising the importance of working together and really listening to each other.

Tackling the power dynamic



Figure 148: Discarded images

The presence of a parent, support worker and researcher situated us as potentially having power over the autistic author. However, use of mixed media enabled each to interact with us, or to discard narrative elements introduced by others and engage in a process that gave precedence to their own priorities. This was particularly evident with the crafting of Sophie's collage, and also characterised Peter's mind mapping process. In the case of each, the media allowed the autistic author to take control over the process and the final image produced. Discarded images were

there to pursue in future narratives if wished and to become part of a new narrative layer explored by interested others.

The narrative portrayed by the images selected appears to be influenced by a medical model perspective, which presents the autistic individual as dysfunctional or inept (Baron-Cohen, 2008; Happe, 1994a; Shah and Frith, 1983) and is strikingly different to that presented by the autistic authors alone. This perspective was reflected in some of the terminology used by parents and discarded by autistic participants. Interestingly, some themes, storied by the parents, demonstrated social pressures imposed by a 'normative' approach to becoming an adult.

The process of narrating using diverse narrative genres took place over time, and autistic participants adapted media to story themes or plots relevant to their lives in that moment. As such, there was increased potential for reflecting on and addressing the perceived or actual power impact exercised by individuals present throughout the narrative period. Perhaps for this reason, this enabled power to be addressed at various locations throughout both the production and the image produced (Lutrell, 2010; Wiebe, 2013).

Real life experiences



Figure 149: Real life experiences

A key theme mentioned by all three of the autistic authors in my study addressed anxiety, although this was done in entirely different ways.

Firstly, anxiety was the theme selected in relation to problems and worrying and the need to develop a strategy. The experiences introduced resonated with me on a wider scale since joining a new activity makes many autistic or non-autistic people anxious. However, what is more at issue is the degree of anxiety experienced and the impact on general wellbeing. Choosing to access an activity independently, locates control

within the individual. Alternatively, should others be more in control of your activities, in their eagerness to see you succeed in life, this locates power in their hands and can render the [autistic] individual feeling powerless.

Secondly, there was a clear message as to features that could provoke anxiety and in the worst case scenario result in exclusion, and as an audience I had witnessed anxiety both performatively and within the images of both Michael and Peter. Michael required frequent cigarette breaks during the collage sessions despite his enjoyment of them (as told to me by both his mother and support worker). This suggested to me that perhaps the context or the process of relocating power were challenging for Michael. However, his tenacity to express himself and be heard overrode his anxiety as each time he returned to work further on his image. The impact of anxiety on Peter manifested itself differently. I had interpreted his physical behaviour as anxiety in response to a range of factors, namely an overstimulating environment, a new activity, a new person (me) introducing the activity, and instructions that could perhaps have been better presented. Nevertheless, once focused, his anxiety began to dissipate, and he was able to remain in one place, where he storied a list that included elements that worked for him. The images regarding the need for clarity, which in turn might be more enabling, were useful to include in the bigger message about distress. It was useful to have a collection of narratives within which to locate this as they trigger

alternative perspectives and questions which may assist in clarifying specific points.

Thirdly, there was the revelation that one of the authors had developed what they believed to be coping strategies, and my interpretation of these backfiring is that they may well have induced or augmented anxiety. This was evidenced by Michael's corroboration of the role of anxiety expressed by Sophie, and which had led to each developing coping strategies. The images suggest the importance of working with autistic people to develop an understanding and development of strategies that work. This is an important aspect of shifting the power imbalance and the experiences of mental distress to ones of wellbeing.

Influence of context and power on the narrative told

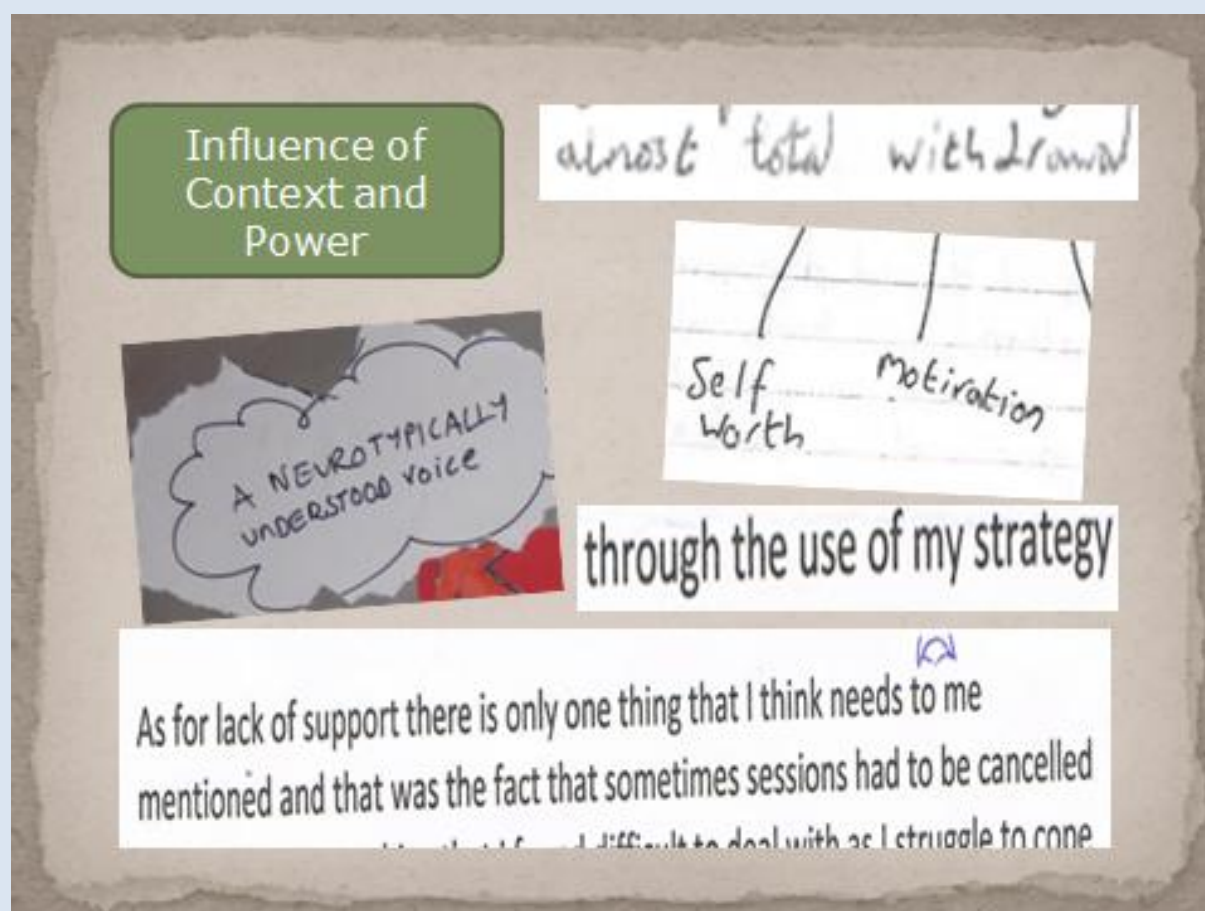


Figure 150: Influence of context and power

The overlap between wellbeing, context and power is a critical issue to understand (NEF, 2012), and this is particularly the case in shifting the narrative focus of autism. All three autistic authors demonstrated, or specifically said, that if context and power were addressed, such that the environment was autism friendly and the autistic voice took precedence, less anxiety was experienced.

The above image produced by the different narrative layers allowed the introduction of an array of themes, sometimes distinct, and sometimes

complimentary. Using mixed media, participants were able to story successes and provide an example of how a barrier had been overcome with support. Individual stories are crucial in enabling an audience to understand details leading to a wider theme and permitted me to maintain sight of the individual, whilst at the same time building an overall impression of how context and power have impacted on wellbeing.

One of the stories within this larger narrative displayed concerned the role of an NT who could understand. This empathy facilitated a process within a context where power was shifted to the individual, such that he was able to become more motivated and experience wellbeing characterised by self-worth. The other narrative concerns a strategy and support to cope with unpredicted change. I felt that these images gave both narratives a sense whereby individuals were distanced from their experiences. Nevertheless, the stories are a key chapter in the bigger picture of the impact of context, power, wellbeing and empathy (Milton, 2012a; Milton and Bracher, 2013).

Intersectionality



Figure 151: Intersectionality

Intersectionality, or the impact of oppression (Bloxall and Beresford, 2013; Liasidou, 2013), was only storied directly by Michael in terms of gender. However, there were storied themes around change, support and perhaps needing to recognise more than one part of an identity. These images also indicated to me that this theme implied intersectionality, as in the 'we' used in relation to 'support, we need it' or 'there's more than one you'. However, this needed to be explored further.

All three authors chose to story images of oppression regarding their support requirements, and this was placed in the context of an individual 'Aspie bloke' or a group membership, 'Asperger syndrome', either in the form of what support to provide and how or the impact of not addressing these. It was interesting to me that the storying of different contexts emerged either in their impactive difference on the procedural image, or as a facilitatory factor in the storying of more challenging tales. In terms of tackling intersectionality within these collective narratives, the image I have storied shows how power was located in terms of ownership of process and production and prioritising of the final image.

Discourse



Figure 152: Discourse

These images spoke collectively to me demonstrating distinct communication roles and styles, and they reminded me that in engaging with this theme, I also had choices around engaging with various storylines. This inevitably gave me an element of power as the ignoring of a plot deemed important to the teller could have a really negative effect on an already vulnerable individual(s). This relates to the role of power within the institutional context, and if for a moment I adopt Foucault's position (Phillips et al., 2004), that power relations characterising the social world concern discourse at a specific moment in time, the settings

across which my data sets were gathered point to a number of interesting features.

Both the narrative texts and collages occurred in a range of different contexts, and the process of power situated within this varied accordingly. Sophie's narrative may have been produced on her own or with her support worker and/or mother present; alternatively, it may have reflected a sharing of power with a concern for perfection and accuracy with spelling. Joint text and production provided an opportunity for discussion about content, although Michael did not engage in this, and Peter worked alone. With both media, staff or family could provide their own perspectives, discussing images provided, and this could be either constructive or destructive. The various contexts allowed turn-taking during the production of the collage, and the text produced by Sophie may also have involved this. This is an important factor to consider in terms of the location of power within specific contexts (Fairclough, 1992). The storylines that emerged in these instances validated the contribution of a support worker to the lives of individuals, but for me, at times there remained a question as to whether, or how, discourse had taken place. This suggested that non-autistic 'others' may have had power over the story told. Conversely, other sections of a narrative pointed to a fusion of ideas and the negotiating of goals, and this rang more with a flavour of power between individuals.

The image relating to romance aroused my fascination as I wondered whether this was something discussed privately or whether in using the image, it was ripe for discussion both as a topic and as a life event. The exploration of media allowed discourse to be variously addressed: by the raising of new themes; storying discomfort about how things had occurred, allowing distancing of the autistic voice to take place, as in 'there was a miscommunication'; and by encouraging and embracing a more active communication style, such as listing what works. The diversity of discourse is displayed in images relating to the past, present and future, and the distinction between active and passive roles regarding discourse are interwoven with both context and location of power. Importantly, opportunities to develop themes are emphasized.

Ongoing discourse through the mind mapping and collage processes may have enabled autistic authors to either listen and include or exclude chosen themes, or to 'zone out' completely and focus on their tale. All options are available to authors storying in the moment, and I felt that the audience mix, comprised variously of a combination of me, the support worker, a mother and a girlfriend may have facilitated the storying process. Rather than taking power away from the author, the power balance in the collage process appeared to be shifted in favour of the autistic author. That said, I also believed that each author wanted to express themselves regardless of the imposition of context or power. For this reason, I wondered whether any 'outsider' power was, in these

contexts at least more related to a 'shared power', with all present being keen that the autistic narrator storied their experiences. The 'in the moment' functioning of memory, imagination and narrating, intertwined with fluid identities and pointed to a picture which required constant scrutiny in order to address changing perspectives and storylines.

This theme demonstrates that in relation to this study, context and space can be seen to be both a 'location for discourse' and 'as a topic of discourse' (Benwell and Stokoe, 2012). Sophie appeared comfortable working on a table with some familiar people present, and able to explore some challenging topics. Performatively, Michael was more at ease working alongside his girlfriend and Peter defined his own space for himself alone, and the images show possible reasons for this. Each seemed to contribute to this process of defining their working space and taking ownership of this.

Important to describe under this theme is the unseen context of the ambient environment as it played a key role on storying. As my collection of autistic narratives progressed, I was constantly reminded of the impact on discourse and our understanding of messages being relayed (de Fina and Georgakopoulou, 2012). The location surrounding the production of Sophie's image was quiet, used natural light and conjured up a relaxing atmosphere. In this relaxed setting, she was able to develop her subplot of anxiety, as seen in her narrative text, to form a more impactful and

detailed theme linking images by using the collage (Wiebe, 2013). The context, in which Peter produced his list and Michael his initial collage draft, was extremely noisy, smelt stale and had artificial lighting. In this environment, both referred to more immediate concerns such as a need for a small group or a neurotypically understood voice, and rightly or wrongly, my interpretation of this was so that the effects of sensory overload be understood and acted upon.

6.3 Turning Points

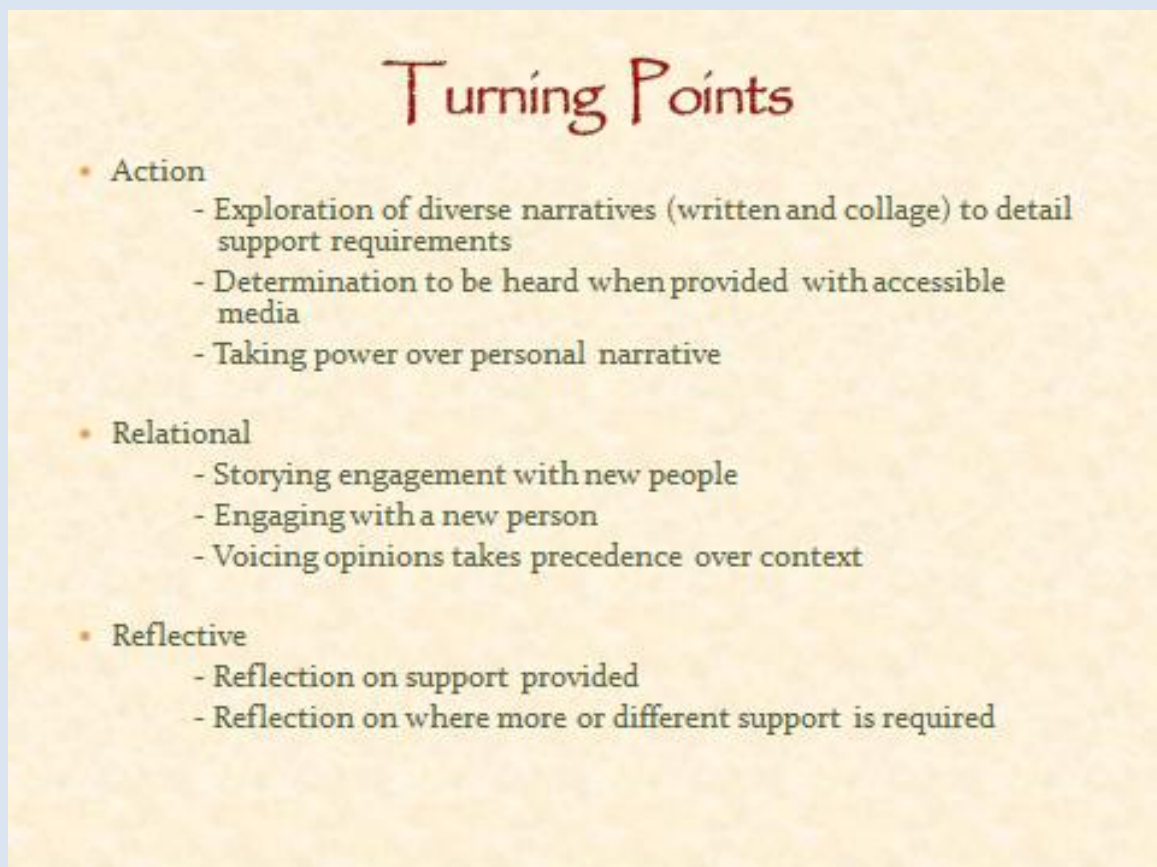


Figure 153: Turning points (author's summary)

My data sets illustrated a number of turning points, and as it is important to note that the concept of turning points is 'determined by the interpretation of an individual' (Negroni, 2012, p43), in relation to my study, I define turning points as occurring on three different levels as illustrated above.

Action

As regards my first research question, whilst all three individuals had chosen their media for expression differently, the mixed expressive media enabled each to process their feelings and thoughts about themselves in diverse ways. As one of the sites of meaning making, it was demonstrated that over time, the actual process of engaging in different methods to express themselves enabled individual participants to reflect on their life experiences. This was not only evident within data sets (as with all three case studies), but also across data sets (as seen in the data sets provided by both Sophie and Michael). Michael's text, including the pie-charts are an example of how he authors past negative experiences, analyses the areas where he was currently receiving support and stories how this has changed his present life experiences on a daily basis, but with potential for future opportunities. I find this interesting as an audience to this, because Peter's narrative taken on its own could lead me to believe that the mixed method approach I used was perhaps not effective. However, the fact that Sophie's narratives also storied turning

points indicated to me that more time was required to enable Peter to develop his narrative.

There was a determination to be heard, which was apparent when accessible media were provided, and these led to a situation whereby power could be passed to the autistic author or actively taken by them to story their experiences of autism. For this reason, I was equally able to learn about interests and what type of environment is enabling. This was important in opening an area of discourse that has potential to shift the autism agenda to one of wellbeing.

Relational

Several of the narratives storied engagement with a new person, so the bigger picture demonstrates progress in terms of inclusion by 'outsiders', and a process of engagement with autistic people working on their terms by listening to their voices. In addition, in order to story this engagement, further engagement with a new person, me, was required. Whilst this may have been challenging for authors, context and power appear to have played a lesser role in this process than the need for each author to story issues directly relating to their wellbeing. The identities storied contained a dominant narrative relating to wellbeing, although other themes existed.

Reflective

Authors were very clear as to what support had been provided and how it had helped. Messages for future service providers were also given in terms of current support requirements and, in the case of Michael, the role he would like to play in this. This broader perspective is useful in terms of asking others if specific issues unaddressed by them are also relevant. Peter storied an environment that could be enabling or, if not addressed, could exclude him, and this reflection was a really critical insight as it reflected the views and experiences of many autistic authors mentioned in previous chapters.

Summary

Using my research questions and theoretical and analytical framework to guide this chapter, I have presented a flavour of collective themes that arose across the narrative data sets of all three individual case studies. Nevertheless, this is in no way intended to detract from the experiences of each individual author, since whilst similar themes may be raised, the way in which they manifest themselves may be entirely different, and it is these individual experiences that are the central focus of my study.

The following chapter discusses my findings in relation to the individual case studies locating my study within current research, and I highlight the importance and relevance of them for service provision.

Chapter 7: Discussion

7.1 Introduction

It has been argued that social researchers have 'romanticised narrative voice at the expense of narrative analysis' (Atkinson, 2009), although in the field of autism, narrative has paid attention to the latter and focused on the medicalisation of autism at the expense of the former (Parsons et al., 2009). This discussion will show how using my theoretical framework I can bring narrative voice and narrative analysis together in a meaningful way to inform service provision.

To remind the reader, the initial motivation for my study was due to family experiences, where my family diversity has led to a range of challenges, bringing happiness with the successful confrontation of obstacles, and sadness when people I care deeply about have been excluded, faced rejection and not been encouraged by others to be 'comfortable in their skin'. Discourse throughout my data collection often exposed sites of similar experiences, although detail was not always discussed, and this stirred many emotions. The re-telling of autistic participants' experiences, therefore, was an extremely difficult task due to the negative impact of historical and current ignorance resulting in the misdiagnosis of someone close to me.

This chapter now discusses the relevance of my findings in the light of what Sophie, Michael and Peter did and did not voice and places these in the light of implications for the construction of inclusive and relevant services. I have presented this as a separate chapter as I wished the autistic voice to stand apart from that of other authors, whose narratives were included earlier in this study by way of illustrating distinct agendas and terminology.

I begin this chapter by exploring the double hermeneutic in my study, looking first at some possible identities participants may have had of me as this relates to audiencing. I then discuss how I made sense of the way in which each author storied their experiences. The third section considers whether these stories are new to the field, and finally I reflect on untold stories.

7.2 The Double Hermeneutic: making sense of autistic people making sense of their world

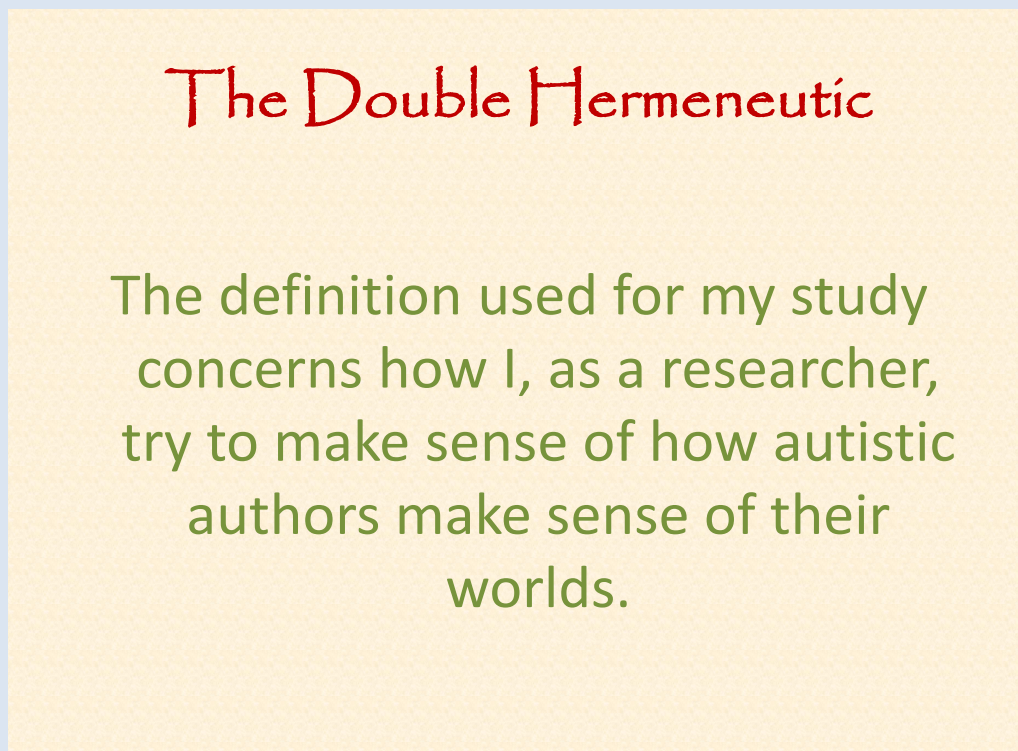


Figure 154: Definition of the double hermeneutic for my study

The double hermeneutic arose in my study as a direct result of my wish to place the autistic voice (insider) as the expert and by then interpreting narratives told. My study acknowledges that as the insider experts of their experiences, the voices of autistic people are frequently pushed to one side in a world that sets normative standards and favours non-autistic (outsider) others. This required a creativeness in my research design that did not shy away from flexibility as a core feature of inclusive practice. For this reason, autistic people informed the development of this creative approach, which I believe fits with both legal requirements and moral and

social responsibilities regarding inclusion. As such, this was an important aspect of my study.

My research paradigm, design and choice of methods were informed by my pilot study, the subsequent evaluation of a regional support service for autistic adults and teens, and influenced by my various identities, and those of autistic family, friends and colleagues. This embraces the concept of 'neurodiversity', which links with the social model of disability (Oliver, 1999) and psycho-emotional disablism (Reeve, 2015; Thomas, 2007a, p152), the disabling barriers of society and the right of individuals to focus on different abilities and identities. A key feature of my methodological approach is that it is informed by both autistic and non-autistic people, which sets it apart from many studies to date (Brook, 2014; Milton, 2011b; Sinclair, 1993).

My identity as a researcher and participants' perceptions of me

My identity as a researcher interpreting my data was influenced by Hall (1996), who postulated that interpretation of a text is heavily embedded in our own assumptions. In addition to these, I considered that provision of the data itself might have been influenced by possible perceptions participants' may have had of me. This relates to an argument put forward by Luttrell (2003, p166), where she points to a double problem embedded in the double hermeneutic regarding the representation of others. This problem concerns three main areas:

- authority regarding the basis of my knowledge;
- culture concept, which includes othering and may result in the reduction of diverse individuals to a homogenised group;
- appropriation or the use of the experiences voiced in my study for my own research purposes.

Consequently, I felt it necessary to look at some of the possible identities that autistic authors may have had of me as audience to their narratives, as this is interwoven with the communicating and de-coding of a message. A difficulty at this point can result in the transmission of an incorrect message. As such, I reflected on my identities and believe there to have been three main perceptions participants would have had of me, and which would possibly have influenced their selection of experiences narrated. The presentation of these perspectives enables readers to arrive at their own conclusions about these influences on my interpretation of the autistic narratives presented.



Figure 155: Possible perceptions of me by participants

Service evaluator

At the start of my PhD study, I formed part of a team of three researchers from the University of Birmingham Autism Centre for Education and Research (ACER) asked by a head of service of Adult Social Care to evaluate their regional support service for autistic adults. As such, the first perception autistic participants could have had of me was as a service evaluator.

The support service, established in the winter of 2009 in response to an expressed lack of support by autistic adults and their family members, aimed to address the needs of autistic individuals who were not FACS eligible, and for whom there was, therefore, no statutory service provision (Ridout et al., 2011). Participants in the evaluation may have been

concerned that my involvement in the evaluation was related to the continuation of their service. This may have caused anxiety about support being stopped, subsequently influencing experiences shared. Consequently, I was in a position of power as a potential 'audience to be won over', and this may have impacted on their narratives. In accordance with the national profile (Arnold, 2013; Brook, 2014; Dunn, 2014b), autistics in the region concerned had not yet established a voice, whereby they could influence the shaping of services. This was, therefore, a new experience for them and influenced my decision to use a combination of methods.

Researcher

As a doctoral researcher, I wanted to explore how autistic individuals outside my circle of contacts conceptualised their experiences and identities, and I introduced myself to people attending a support group for autistic adults. I explained that my purpose in running a workshop activity was to listen to their experiences as stated by them, and I emphasised that I specifically valued their views, I also mentioned that my own experiences with autistic family and friends was that their views were often not asked for, heard, listened to, or acted upon. For this reason, I was, therefore, interested in building a wider picture.

Whilst some autistics may have had family who were eager that the voice of their autistic family member was heard, the family of others may have

perpetuated the cycle of 'the autistic not being the expert in their own experience', and as being problematic (Milton, 2014d). Therefore, the experience of autistic individuals in my study may have been an eclectic mix of good and bad experiences of family support, but I hoped that in being honest about my experiences, this would encourage them to share their own.

As my second identity, it was important to note that simply researching an area does not make one an expert (Czarniawska, 2004a), and that there was a distinction to be made between my profession and my position as interlocutor. My stated position was that life stories place the narrators as the experts as they hold the power of knowledge, even though this may be in stark contrast to the 'expertise' held by professionals working with autistic individuals and service providers. For this reason, my third identity was also important.

Individual

Working with the support group, I was conscious that I had to wear dark glasses due to the lighting in the venue. Consequently, this led me to explain that I am neurodivergent and share many similar experiences and challenges with autistic individuals, particularly in relation to the effects of sensory overload and processing information. I also explained that I recognise neurodiversity as it acknowledges the individual differences in

skills and abilities that we all hold as individuals (Arnold, 1999; Graby, 2015).

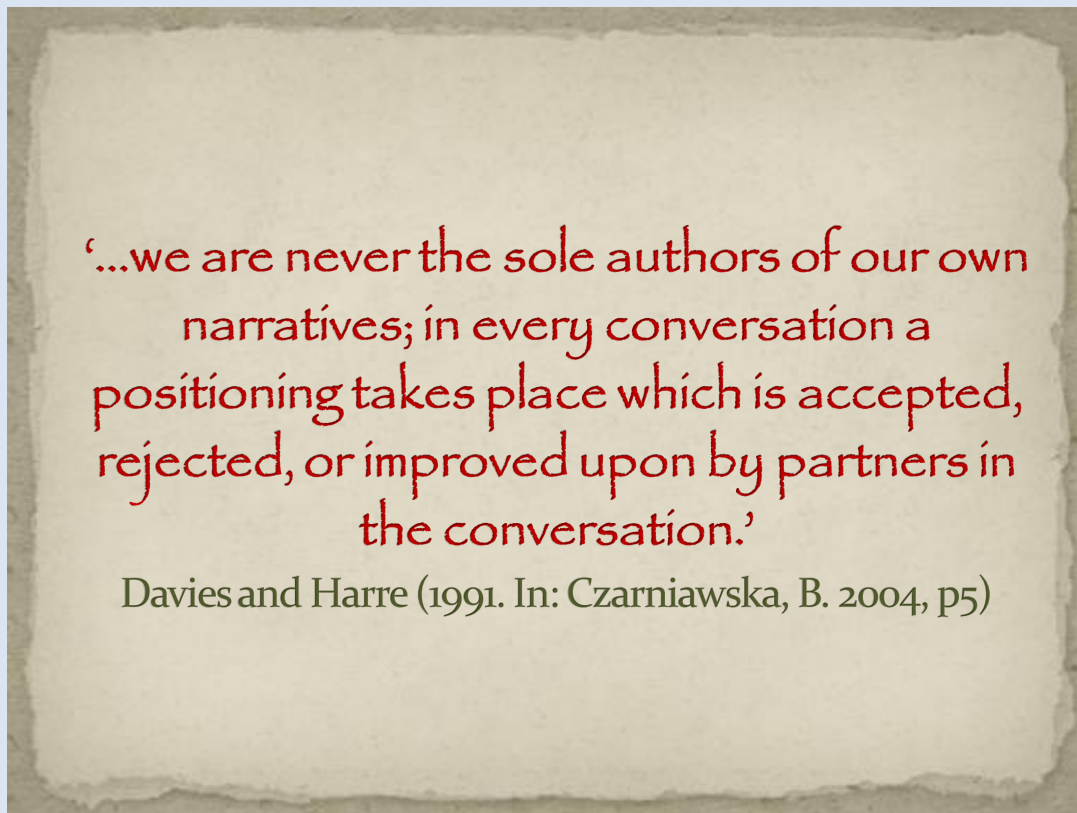
Whilst some autistics' anxiety about my role as a researcher and evaluator of their support service may have continued, I hoped that my insider-curious outsider (neurodivergent) perspective may have resulted in at least some feeling more comfortable storying their experiences to me.

Making sense of the narratives

As with Chapters 5 and 6, I will present here some of the main issues that have arisen in respect of each case study and discuss these in relation to my research questions. As stated in my literature review, giving voice to autistic experiences, as expressed by autistic people themselves, is under-developed in research (Milton and Bracher, 2013), so the focus on insider (autistic) knowledge is critical to my study.

The presentation and interpretation of my individual case studies and meta analysis of data explores and supports the importance of visuals in my study (Lawson, 2011), and I believe this demonstrates how they were essential in the progression of my thoughts as the new narrator. In investigating the double hermeneutic, I was interested to review how autistic authors storied their experiences, and whether use of different narrative tools assisted in the description and explanation of their experiences. In addition, I wondered whether these enabled them to

imagine new possibilities, which opened up opportunities for discourse with others.



Another key aspect of my making sense of the narratives of each individual author concerned acknowledging that the data is subject to many different interpretations, as I have shown in Chapters 5 and 6. For this reason, my presentation of this section again looks at some key themes which address my research questions, and which are critical in the provision of appropriate and relevant services. I begin each section with a visual image that the narratives had conjured up for me of each author.

Making sense of Sophie's authoring



Figure 156: Double hermeneutics and Sophie's narratives

Sophie left me with the impression that there were many layers to her, told and untold stories and experiences. I visualised her as a many-petalled flower, where each petal was able to furl and unfurl as she developed confidence. The delicate centre, which perhaps represented her anxiety, was always central to her identity. These are her stories as I have made sense of them.

Feelings and thoughts

Priorities

I found the conflicting narratives of Sophie's diary and collage to be initially baffling, as reflecting with Sophie on her experiences in a manner that was more organic appeared to enable Sophie to introduce what on the surface appeared to be a conflicting theme, anxiety. This seemed to be at odds with her achievements. However, although both narrative layers were important facets of the wider narrative relating to Sophie, Sophie's involvement meant that her influence over the knowledge production about autism attended to her own autistic agenda – there may be successes, but anxiety is part of me.

In re-telling a narrative, there are some distinct advantages, as it keeps the story alive. Consequently, I was able to gain a sense of how Sophie was able to focus and refocus her narrative on themes of unhappiness, dis-ease and anxiety. Despite stories of success, which emerged in the narrative diary worked with her support worker, these themes of distress occurred at intervals through all parts of her narrative diary and collage process. The importance of this points to a need for service providers to assess the support requirements of autistic individuals at intervals to reflect changing situations.

Silence

My presence and involvement with the collage process enabled me to see how Sophie participated in activities, at least in the early stages of meeting someone new. She seemed to be absorbed with the activity, listening carefully to my suggestions as to possible steps to progress the activity. Whilst I was worried that my approach at this stage may have been too prescriptive, the final collage left me in no doubt as to her ability to assert herself at times. This was interesting, since she was silent throughout the whole process unless asked a direct question, as in the purpose of posters. Nevertheless, the disconnect between the different genres of the narrative diary and the collage allowed her the space to present images that 'argued' with each other, to draw me as audience into her experiences. Perhaps more importantly, as a social actor, Sophie would have been shaping her life retrospectively to reassess her memories and to make sense of these. This is a point discussed by Riessman (2003) in relation to other areas, but which I believe has much to offer autism research in terms of making sense of past experiences.

Overall, at this stage of narrating, Sophie presented an inner-outer turmoil between herself as a more confident independent person, yet this is linked to her support, and someone whose life is characterised by problematic themes. These were illustrated in the collage, where the presentation of her 'confidence' is literally visually broken. The power

behind the depiction of her feelings in this manner is readily accessible to those who wish to address Sophie's support requirements.

Tension/Dilemma between methods: working discursively with the client or in a linear fashion

The flexible manner in which my methods were accessed by Sophie meant that intersectionality could be addressed (Simone, 2014). Rather than insisting that she worked only in a linear fashion that did not permit her to adjust her storyline, Sophie was able to completely change the story she wished to tell. In this way, one genre allowed her to work on points of contrast (Riessman, 2008). There did remain a question in my mind as to the storyline she would have crafted had she supplied her own art materials. Certainly the images would have been different, as her distortion of these, linking several with another medium, crayon, had allowed her to move back and forth between images and to have a type of discourse with her mother's narrative. This type of visual discourse is powerful (Foucault, In: Rose, 2001, p137) as with an absence of rules, it allowed Sophie to construct her identity as she wished.

IPA provided me with the opportunity to consider the clusters of words that Sophie used, and I was able to see that linking these in themes relating to plots concerning problems or success worked well for her in both the narrative text and the collage. The narrative layers enabled

Sophie to work silently to provide an alternative vision of herself, and whilst one of the narratives was possibly storied at one sitting, the other, the collage, was storied in bits and pieces in a manner reflective of work by researchers in other areas (Czarniawska, 2004b, p38). This again provided an opportunity for Sophie to remember clusters of experiences or words relating to moments she wished to share, and both stories would be critical for service providers to understand.

The re-telling of a narrative allows authors to emphasize different points and provide an audience with a variety of sites to engage with. In Sophie's narratives, the issue of anxiety told in its different formats as a sub-theme and the dominant narrative, and reinforced by her mother as 'drowning', pulled me in to consider the various impacts it had on her life. It also emphasizes how a flexible approach in interpretative work facilitates the explanation of experiences. Sophie's capacity to engage with an audience was evident given flexible and creative methods, and this point was something I had considered in the creation of my methodology (Rose, 2001).

Nevertheless, Sophie's data points to the dilemma between the value of the different methods accessed to story her experiences, which I believe cannot be separated from the sites of meaning making: the process, image, audiencing, turning points and discourse involved (Rose, 2001).

My methods introduced a certain 'ad hocery' in the form of diverse thought experiments, and my impression of Sophie was that, whereas the authenticity of her voice was questionable in the narrative diary, creativity allowed her to break through boundaries to express herself as she wished.

For an audience interested in seeing progress, for example funding bodies or service providers, Sophie's linear narrative provided a perfect example of a stepped approach to success characterised by support, mentioning some challenges and where a decision about the narration had been made regarding whether to focus on achievements or difficulties faced. However, if an audience such as service providers is only interested in hearing stories of success, funding and services will never be appropriate or relevant (Brook, 2014; Milton and Bracher, 2013). So whilst it is extremely useful in terms of enabling me as an audience to understand progress made, I was also concerned to hear the small story detail surrounding challenges experienced by Sophie. So the story of the image production, in addition to the actual image itself, was critical to this, and I was not present during the production.

To counteract this, triangulation of methods using the collage process was critical in addressing this gap as it shifted the emphasis of Sophie's experiences to a different storyline. Sophie's exploitation of the collage

took her to new realms where she could imagine life beyond her current situation, which framed her as an autistic teen. She was able to recognise problems and their impact on her, but more importantly, she could provide solutions. The way in which Sophie accessed the collage process supported one of the findings of Luttrell (2003), in that it enabled her to look backwards and forwards over the story. This method allowed her to take advantage of her creative communication style, where she benefitted from reflecting and imagining, so changing her narrative accordingly (Murray, 2013). This is the way that we in a neurodiverse society naturally function, by using the methods best suited to us to explain our experiences to others. As such, this is a direct challenge to service providers to engage meaningfully and effectively with [autistic] people, so that this is a process whereby each can understand, or work to understand the position of the other – empathy (Chown, 2014a; Milton, 2012a).

The collage process itself allowed and encouraged reflection on the addition and removal of images at a later date, and indeed permitted the unearthing of conflicting themes as discussed earlier in relation to work by Plummer (2014). On visiting the sites of meaning making in this process, my overall impression was that the image provided by Sophie's mind map introduced themes that were not necessarily immediately positive or negative. However, on placing the themes under headings, a more negative picture emerged as themes were repeated as regards both

feelings and challenges experienced by her in relation to a number of different areas. This is important for 'audiences' trying to understand how Sophie's real life experiences impact on her, as there is tale at this stage of anxiety and unhappiness, and where family are critical in supporting Sophie.

Moving to the next stage, choice of images for the draft collage, Sophie and her mum story current experiences and possibilities that relate to a brighter future. Nevertheless, despite the apparent progression of this narrative, given time to reflect on her images and having discussed the purpose of a poster in providing a clear message, Sophie chooses to return to problematic themes and possible solutions. This is a good illustration of the point made by an autistic practitioner, Lawson (2011), who highlights the role visuals play in the understanding of our own and shared worlds. It may well have been that the textual narrative diary genre did not serve Sophie best in terms of expressing her story, but was important in providing service providers with an understanding of the complexity of narrative layers and themes at play. The presence of one theme or narrative does not necessarily negate the other, rather it highlights the importance of establishing an iterative process to check and recheck support required.

Identity and wellbeing

Assumptions

Sophie's narrative data supports the view held by Sinclair (1993) in that a failure to share temporal ordering can lead to assumptions by outsiders. At no point was it clear that the normative trajectory from college to university, to being independent belonged to Sophie. She was more concerned about 'a good future' and receiving help to manage her current feelings. In fact, I would argue that this was possibly behind much of her anxiety as she transitioned to adulthood. This is important information for service providers.

Attending to gender was additional to dealing with managing her autistic identity, and this may be why the notion of gender binaries was not explored. Simply her difference arose specifically in relation to having a relationship with a boyfriend and having Asperger syndrome. So the oppressive practice frequently referred to in autistic narratives (Harris, 2015) only referred directly to this. Nevertheless, as a young teen, expressing herself in this manner, she did introduce an element of diversity to my study.

Nevertheless, Sophie clearly feels different in relation to some 'normative agenda' as expressed by her mother, and the plots that she chooses to story reflect distress as opposed to wellbeing. Rather, Sophie's position is

more demonstrative of the argument proposed by Bornstein (2013), which points to ways in which individuals can encase themselves or be encased by others in a particular narrative, so oppressing them. This said, her collage narrative, does story a wellbeing approach, but one which is considerably more nuanced than arguments suggested by Seligman (2011) or the NEF (2012, p30), and which would be ignored by the prioritising of the storyline contained in the narrative diary. Both stories need to be heard.

Independence

The sites of meaning making are essential in enabling discourse around identity and understanding how Sophie was conceptualising her wellbeing. With the two distinct narrative processes, I was able to see that one led me to see her as improving in confidence and wellbeing, and with specific interests to explore with new friends. This was set against a backdrop of distress, worry and dis-ease with her identity. Within the draft collage, there was a plot relating to a relationship, and this indicates how the small stories need also to be investigated in the journey to Sophie achieving the lifestyle she wanted. The introduction of my sites of meaning making to my study were, therefore, invaluable as they indicated where it might be useful for Sophie and others to discuss aspects of her identities that impacted on her requirements.

Independence was an interesting theme as it appeared in very different ways. Throughout the narrative diary, the tale provides a sequence of events leading to increased independence. Although some acknowledgement is given to challenges, such as difficulty coping with change, one could be forgiven for perceiving Sophie as more confident and independent than before. This may have been the case, but in the context of collage, she provides an entirely different identity of herself and her wellbeing such that I questioned whether the narrative was one of independence, support or a combination of the two.

In developing systems of support, Sophie's story illustrated how attitudes could lead to unhealthy cycles of dependency, and this is a theme raised by Tew (2006, p7) that has relevance to this area. In a context where she depended on support in order to participate, the narrative diary gave me the sensation that support had been rushed at the expense of exploring how to help Sophie transition from a situation of being powerless to one where she felt more in command.

I was able to listen to several plots in Sophie's narrative diary and her collage relating to turning points. These concerned an achievement (using transport and climbing), contact with a new person, the climbing instructor (relational) and a shift in awareness, for example that her anxiety was being placed as a sub-narrative by outsiders (reflective). So

the narrative genres enabled distinct aspects of the plots to be accessed in relation to a storyline. In addition, I became aware that the double hermeneutic had an additional impact at this point in that if Sophie did anything 'risky' whilst climbing, her identity as an autistic person with support requirements could jeopardise access to this activity. This put power in the hands of her support worker or non-autistic staff to withdraw this opportunity.

On the other hand, I was able to see from the narrative layers that given support, Sophie's talent could be tapped into. In addition, I was able to understand something of the type of support that Sophie had required to access this climbing activity, that various aspects caused increased anxiety, and that this needed to be understood in the context of her as an autistic person finding it difficult to manage her reactions to sudden change and unfamiliar situations. However, in disclosing that she needed support, there was no information provided as to how this had been done or whether Sophie felt comfortable with this. People's perceptions of autism vary widely, as discussed in my literature review, and negative perceptions may also have increased Sophie's anxiety. Debate around disclosure is a constant theme on the agendas of minority communities (Anderson, 2010; Crenshaw, 1989; Crenshaw, 1991; Yuval-Davis, 2007), and particularly in relation to intersectionality. Each situation needs to be assessed separately, with reflection on the advantages and disadvantages.

Context and power

In the telling of Sophie's narratives to readers, I was mindful that the dominant outsider narrative contradicted the insider narrative in several places (Andrews, 2002b), and had I not been keen to position the voice of autistic authors to the fore, this may have silenced those that Sophie, as the expert insider, wished me to hear (Smith, 2014). This is a situation frequently experienced by autistic individuals.

The plot of a story suggests a position of knowing (Czarniawska, 2004b, p6), and this shows the insider-outsider tension in the authoring of autistic experiences. In the process of Sophie's collage, I did not expect her to completely refocus her narrative in the transition between the draft and the final image. As such, it opened up opportunities for discourse. More importantly, it located her in the unique position of being able to speak for herself, and given this access to discourse and increased power (van Dijk, 2008), she wanted problems to be acknowledged, and clear solutions were attached to these. Introducing a storyline from the perspective of success had the unfortunate effect of minimising the severity of Sophie's anxiety or social sensitivity. Whilst layered opinions could be influenced by outsider views, there perhaps needs to be a consistency in service providers' approach to introducing the purpose of the narrative. This would have been useful in the introduction of the narrative diary to Sophie as well as the collage. This could be addressed by relocation of power so that Sophie's fluid identities can come to the

fore. In the context of this study, I was of the view that she had a very real concern that support would be discontinued, so this theme needed to be prioritised.

What was exciting for me about Sophie's artwork was that it enabled me to see new stories emerging as she reflected back on events to demonstrate how she had changed. I wondered at what points these narratives had originated, as it was important for Sophie to have both the problems and the solutions acknowledged and understood. This makes sense, particularly if Sophie is someone who generally experiences a heightened level of anxiety, and by mentioning strategies in the narrative text, this does not mean that anxiety will never arise, simply that she has a tool that she can hopefully access should the need arise. My awareness of Sophie's personal circumstances drew my attention to this final image, and this resonated with a theme raised by Luttrell (2003, p156) concerning the feelings and emotions the experiences of another raises within us as researchers.

Sophie's use of the two narrative genres, the narrative diary and the collage, allowed her to introduce a sharper more linear account evidenced by her narrative text, which contrasted sharply with the softer, more malleable processes of the collage. The narratives worked well individually, but even more so when set together, as here their apparent

contradictions were fascinating in their exposition of key themes which relate to service provision.

A key theme to discuss regarding Sophie's narratives is the issue of power as it presented itself in a number of different ways. The narrative text occurs in a linear format as it is hung together as a sequence of events, each impacting on the outcome of the next and held together by a plot (Bell, 2013). So any reading of this narrative out of context could result in Sophie being perceived as an individual requiring support in specific basic activities, such as using transport independently or accessing leisure pursuits, without a real appreciation of her underlying challenges. In addition, that the narrative mainly stories the steps taken by the support worker as opposed to details of the actual support itself and why it was required, an incomplete picture is provided, which ultimately positions the support worker/service providers in a position of power.

However, when coupled with the collage it became apparent that these successes, and obstacles overcome to achieve them, did not constitute the dominant narrative that Sophie wished people to hear, but possibly contained elements that reflected the agenda of outsiders keen to see her succeed. Sophie's main narrative arose using the more creative collage approach, expressing ideas visually and arranging and rearranging them. As such, Sophie's processing of thoughts and feelings addressed both positive and negative themes typical of those expressed by other teens

her age. Working creatively suited Sophie's expressive style, and this disorganisation and reorganisation of visual images reflected this process. Service providers can take important information from this, as it does show that what may be voiced on one day can be expressed in an entirely different fashion the next, with consequential implications for all.

So for Sophie, the combination of mixed media and creativity allowed her to relocate power in her narrative and position herself as the expert. As she takes control over the storying of her experiences in her collage, she reaches a powerful turning point. Her final collage completely surprised me, and I was particularly interested in the fact that she does not negate the successes, challenges or support of the support worker. Rather, these form a key layer in her wider narrative. For Sophie, it was essential to ensure that a requirement for support remained on the agenda, and she was able to place this as the central theme of a narrative which had anxiety and worry as a basic component.

Authenticity of voice

The importance of triangulating data by using both the narrative diary and collage methods regarding the understanding of autistic experiences was highlighted by Sophie's data, as the discrepancy between the narrative diary and the collage resulted in me questioning the authenticity of her voice in the former. Certainly service providers need to hear where

support is effective, but they need to have a realistic picture showing where, despite support, anxiety still plays a big part in Sophie's life. I would argue that service providers need to constantly review the role anxiety plays in the lives of many autistic people and discuss this using the communication preferences of autistic authors. In this way, possible means of addressing this can be exposed to help Sophie to progress her life in the way that she wishes.

Critically, regarding authenticity of voice, my concern that my identities might have impacted negatively on Sophie's ability to audience her experiences to me as a researcher and evaluator, appeared to have been unfounded. Whether this can be attributed to my more organic approach is difficult to say, but she was able to story both empowering and disempowering situations and where support had been enabling.

Decontextualisation

In interpretative work, context is critical, as an autobiography is set within its wider context (Riessman, 2008), and this becomes apparent in the context of service provision. This is because service providers/funders often do not witness the smaller achievements or the set-backs made by individuals in receipt of support and are not privy to key information as to how they have emerged. Consequently, in terms of goals set along a continuum of achievements to improved wellbeing, these may be

misunderstood and further essential support withdrawn. I believe this occurred in Sophie's relaying of her experiences in the narrative diary, as the distance between her authoring and my interpretation was longer as I had not been directly involved. Therefore, possible distortion of her experiences by me was more likely in the narrative than in the collage.

Focusing on the context of Sophie's narrative, my attention was drawn to her autobiographic construction, which enabled me to understand her concerns in relation to the social contexts she accessed (Phoenix, 2012). Sophie's final collage image ignored a number of other themes, which had arisen earlier such as love and romance. Instead, there was a sense that the anxiety storied better reflected the current context, where there was a question as to the continuation of funding and possible pressure on her to achieve. As audience to this story, I would be reporting back to people who could influence this, and I was cognisant that this possibly impacted on the prioritising of themes.

I believe that Sophie's successes needed to be heard in the context of her support, how the narrative diary was introduced and worked on (details which I did not have), but that there needed to be more openness as to the narrative mission. It is particularly important, therefore, that progress towards independence is kept in context and reflects a stepped approach drawn up with autistic people making the final decision as to desired

goals. This is more likely to encourage an understanding of the fluid identities of autistics, a realistic appreciation of achievements made and support that is still required. Service providers have a responsibility to understand how autistic authors order events personally and temporally as this provides the context for their experiences.

As part of my theoretical framework, Critical Realism allows me to attend to the autistic voice by acknowledging context and considering the location of power within this. Reflection as to whether these impose limits on a story is important, since this may result in the shifting of an agenda towards the non-autistic outsider voice. I believe that in their desire to point to additional themes in the big story of Sophie's experiences, her mother and support worker's stories could have inadvertently covered up the dominant narrative that Sophie wished to tell. This facet is one which service providers need to consider.

Summary

Making sense of Sophie's narratives raised interesting challenges for me due to the turning points introduced in relation to conflicting storylines. Nevertheless, I would urge the reader to consider for themselves how they would have made sense of these tensions within the data.

I now discuss my second case study.

Making sense of Michael's authoring

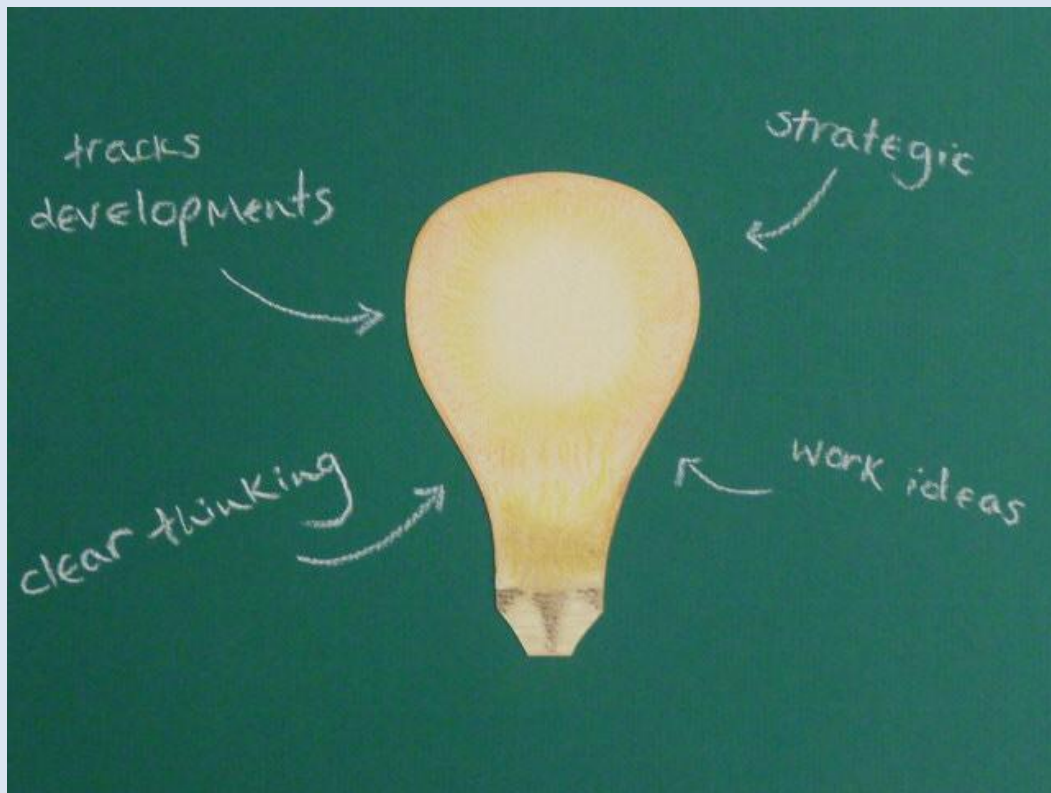


Figure 157: Double hermeneutics and Michael's narratives

Throughout Michael's narratives, I had a visual image of him as represented by a light bulb, an object that shines light on different situations. I had the increasing impression of someone who had so much to offer the employment sector if people only gave him time to express himself and to really listen to what he was saying. The following shows how I made sense of his stories.

Feelings and thoughts

In reflecting on the purpose of Michael's narrative, it was evident to me that he wished to relate a progressive story using the narrative text and

the collage to demonstrate how he had moved from a position of powerlessness to one where he felt more in control.

Mixed media

Michael engaged with both the narrative diary and the collage, to story his experiences. However, he took advantage of the fact that these were adaptable to suit his authoring style. In addition, due to the flexibility of the methods, Michael was more able to deal with sensory and social overload as he could make use of different environments and timescales to assist with the processing of his thoughts and feelings.

The grouping of words by Michael in his diary allowed him to touch on past problems and the feelings they had stirred, reflecting on his life using a new framework. This is reflected by the language he uses and then continues in the collage, which shows that he voices an awareness of 'identity through difference' (Tajfel and Turner, 1979), whilst at the same time an identity through commonality (Appiah, 2000). IPA draws on the clustering of words, and this is useful in highlighting how, in the latter part of his narrative journey, Michael grouped words in such a way that he used language popular among non-autistic people to 'other' autistic individuals. Whether he saw himself in this light or was merely repeating terminology at this stage is unclear, and it is also possible that in discussions with his support worker he had been provided with

terminology to help him reflect on his individuality. Nevertheless, the language reflects a one-directional approach to empathy in that the non-autistic other needs to help [autistic people] to express themselves.

Having moved through the narrative text in a linear way to story his journey from a point in the past to his current situation, Michael identified a theme that was important for him to place as his dominant narrative and explore in further detail in his collage. Consequently, the latter was able to enhance the earlier theme of support. In plotting his narrative he was able to locate his authority in relation to his experiences, and this is a theme echoed by other autistics (Ne'eman, 2010).

In producing the collage, Michael reinforced the point made by Lawson (2011) regarding the role visuals play in the understanding of personal and shared worlds. He was able to place his thoughts around a central visual message of 'expectations from a support group', such that my attention was focused from the outset. This is critical information for those who are wishing to access the thoughts and feelings of autistic people about their support requirements. Methods of engagement need to tap into communication preferences, and in many cases, this requires visuals and time for exploration.

A further benefit of my creative methodology is that it encouraged people to think differently (Robinson, 2010; Robinson, 2006b) and to express themselves in different ways, imagining new possibilities (Andrews, 2014). Michael had missed much of his schooling, and as he demonstrated at the end of his collage, being creative had been a challenge for him, yet it had enabled him to story new outcomes. This is essential to acknowledge in the development and informing of inclusive processes. Furthermore, as an artistic activity, it had provided him with an opportunity to develop new skills and possible future interests. As one way of doing this, he added a performative element to the collage process, which provided me with further information as to possible sensory/social sensitivities or anxiety around new activities or change. Consequently, I was able to be more attentive to ways in which I might offer support.

Stories of now and then

In the recounting of his experiences, I was under the impression that for Michael to be able to tell me how he felt in the moment, it was necessary for him to go back to some previous moment in time, telling a story of past and current experiences. Very often the temporal ordering of experiences, particularly those told by marginalised individuals, is ignored, and I would argue that this is frequently the case experienced by autistic people endeavouring to explain moments of distress. Temporal ordering provided the narratives of autistic authors, such as Michael, with

a context, and the importance of this is a key point argued by Riessman (2008, p24). Also emphasised by Sinclair (2012), the point concerns assumptions by non-autistic people, which in the context of Michael's narrative could point to a misunderstanding of the accumulation of stress and its negative impact on his life.

In re-telling a narrative, Michael was able to retain an issue on the table for discussion, but his interpretation of this experience and the re-telling of it are subject to change. This information was critical to service providers' understanding as to the emergence of Michael's current identities. Each time he retold his narrative, there was a new aspect emphasised to reflect the changing over time (Bansel, 2013), providing me as audience with diverse points with which to connect. As such, Michael was able to shift his narrative from where he storied feelings of frustration to one where he was able to express himself more assertively.

As Michael utilised the methods in the storying of his life, it made me wonder whether working in this way enabled him to process his thoughts about frustration and isolation. As an approach that welcomed communication nuances, maybe it was enabling in that he began to link his feelings to an inability of others to understand autism (Baggs, 2003; Connor, 2013), or even his own difficulties at voicing his support requirements. It was not a prescriptive approach, and so allowed the

experimentation with ideas surrounding a current issue characterised previously by limitations, to develop.

Identity and wellbeing

Of the three narrative case studies, Michael's was the one that addressed the issue of neurodiversity (Arnold, 2012; Murray et al., 2005; Robertson, 2010b). As a narrative which mentioned diversity and oppressive practice (Harris, 2015), he also mentioned his gender, although the intersectionality of these was not further explored. In a sense, Michael's storying of his change from a position where he was quite solitary to one where he is now involved with a group and organisation with resources shows how he can link these changes to specific past and present events.

As with Sophie, the themes attended to in Michael's narrative addressed a more nuanced wellbeing approach than that characterising the NEF agenda (NEF, 2012, p7-8), as issues such as inclusion, being understood and help to communicate are mentioned. However, the autistic voice on these issues is being ignored. Without using those exact words of 'happiness' and 'wellbeing', Michael does demonstrate that he is not happy and that his wellbeing is poor as he is not satisfied with his lifestyle. Further confirmation of this is that factors embedded in wellbeing (positive emotions, engagement, social connections, meaning and purpose and achievements) do not characterise his life or Michael as

an individual (Seligman, 2011), in fact, they are storied. However, Michael's counter-narrative is critical in the telling of new stories; stories of change (Plummer, 2014), and particularly from an oppressed sector of society. His collage compliments his narrative diary, demonstrating how a shift from not being heard to being able to contribute positively to a group has had a tremendous impact on his wellbeing. I would argue that this shift enables outsiders to understand more readily how inclusion can impact positively both on individuals, groups and on society.

In the creating of his collage, Michael challenges the normative narrative [of autism], creating space for himself to be part of an autistic identity yet at the same time stating his expectations as an individual within a group membership (Appiah, 2000). This was Michael's experience, his voice, and it was there to be engaged with by an audience to this at the different sites of meaning making: process, image, audiencing, discourse and turning points, which were available to enhance and expand the debate.

Intersectionality

Using text, Michael was able to demonstrate the impact of intersectionality on him as an Aspie bloke. Consequently, he situated the storying of his anxiety in the context of this identity, and so his mental distress became directly associated to his difference. Being able to use a text to narrate issues of intersectionality and the impact of anxiety

enabled him also to indicate where life had begun to change for the better, and I found his dividing up of his day into feelings and activities invaluable in assisting me to understand their possible influence. In adding to his storyline through the collage process, Michael demonstrated the use of a flexible approach to narrative work in halting systems of oppression. This supports the voice of other autistics (Simone, 2014).

Disclosure is an issue that is intertwined with identity, and the debate as to whether it is a positive move or a negative one depends on both the individual and the context. As a history of misunderstood anxiety and abilities had formed Michael's past, coupled with a difficulty establishing normative routines, he has tended to blame himself. As autistic authors have observed, the diversity of autistic people should inform inclusive practice (Graby, 2012; Lawson, 2001; Murray et al., 2005), and I would argue that this also concerns systems relating to disclosure. In both othering non-autistic people and disclosing, it could be argued that Michael was encasing himself in a single identity (Bornstein, 2013), that ultimately had the effect that 'others' saw his challenges as opposed to his skills.

It has been observed that the restrictions of cultural norms regarding any individual often lead to distress, and this is a really important issue in relation to staff training and the voice of autistic people who may be

experiencing mental dis-ease, due to the impact of misdiagnosis of autistic people (Andrews, 2006). The locating of an agenda outside the individual (social model of disability) as opposed to within (medical model of disability) demonstrates a readiness by practitioners to listen to the expert [autistic] insider. As Michael's situation demonstrates, this is essential in order that his wellbeing can be afforded the attention it deserves and to enable him to contribute to society.

Skills: planning and organisation, co-ordinating and contributing to meetings

The specific naming and storying of skills was not alluded to by Michael. However, it became apparent to me during his collage that he had strong organisational skills and an ability to think and express himself clearly if he felt valued. This substantiates the view put forward by Beresford (2013b) in relation to survivors, and was also corroborated by the data from the plot storied by Michael concerning his contribution to the establishing of the support service in the region.

Michael's narrative diary showed that he certainly had an interest in developing strategies, and that some assistance with developing these skills would be useful for him. In addition, he was able to demonstrate his organisational abilities by using pie-charts, a mind map and then his collage. At several stages, Michael's storying illustrated turning points

relating to actions (reworking a collage), relational (working with a researcher) and reflective (thinking back on how past events had led to his current situation, which he was working to improve). All of these left me in no doubt that he had a contribution to make to society, yet he was currently unemployed and had been excluded for much of his educational years. Potentially, any or all of these skills could feed into the development of a support group or other group/project, and this is definitely an opportunity for potential employers to explore.

It was clear to me as I worked my way through Michael's images and watched his performative narrative of the collage, that 'mistakes' had played a part in his formative years. However, he was eager to challenge what had become an unhealthy cycle of dependency on his parents. Using the narrative layer provided by his mother, I was able to see how the impact of systems and attitudes held in educational establishments had impacted negatively on Michael and also led to his mother's frustrations at her son's abilities not being recognised.

Context and power

Being placed in a position of power, Michael took control of the story of his support to state his expectations. This contrasted with his narrative text, where his story focused on how he was involved in decisions about

his support, but that the overall control for support provision rested in the hands of the outsider.

Communication

It became evident as Michael's narrative progressed, that being in a position of power to tell me directly about his support emphasised his growing assertiveness (Tew, 2006). His earlier statements about his high anxiety and low tolerance levels were almost a statement of fact, and did not seem to relate to self-blame. However, this contrasted with his frustration at his inability to establish effective coping strategies, and at this point he began to recognise his difference from others.

As he gradually took control over the narrative processes, I felt that the authenticity of his voice was clear as he enhanced his text about the use of a visual strategy developed with his support worker to help him structure his day. This reminded me that the way in which I receive information is such that visuals assist with my understanding, and I saw this at the point where Michael added pie-charts as visual illustrations. Although Lawson (2011) argues the importance of visuals for autistic people, they can be important for a wider audience, and my position is that we all have our communication preferences. However, had I not been able to understand Michael's message at this stage of his storyline, this would have carried through to the subsequent report. So both the giving

and the receiving of information are impacted on and warrant attention in the establishing and delivery of effective services.

The processes suited Michael well, as they did not demand verbal communication, rather he engaged attentively in the surrounding discourse, responding occasionally. My framework has allowed me to see and understand his experiences in a unique way, where possible discourse with his support worker has also enabled him to express himself differently. My methodology was one that permitted Michael to work to his strengths and relocate power in terms of the development of the narrative themes that he selected. As such, it established an agenda for discourse with service providers in the future.

Independence or support

It is interesting to muse over whether Michael's narrative concerns transition from a situation of dependence on family, to one of isolation, to support and then to independence, or whether his will always be a story of support. In evaluating spending, this often becomes the concern of service providers and funding bodies (Ridout et al., 2011). So the refocusing of a narrative, such as that done by Michael in his collage, is of the utmost importance as it opens up opportunities for discourse. Has the support provided been effective? Was it sufficient? Does the delivery need to be changed? These questions need to be addressed directly without

ignoring tricky answers. However, without access to public discourse (Milton and Bracher, 2013; van Dijk, 2008), autistics are unable to influence and shape debate. The double bind as seen in Michael's case, and described by his mother, is that without support in the first instance, he would not have been in a position to voice his thoughts on autism. Certainly at the time of his narratives, he demonstrated an enormous journey in the framing of his autistic experiences – from excluded and anxious to being able to participate and be more in control of the impact that situations had on him.

In switching the agenda to one of success and insider knowledge production, it is interesting to speculate as to whether this enabled Michael to manage anxiety and sensitivity-related issues during the process of the narrative production. This may also have been reflected in his ability to engage with his audience (Riessman, 2008; Rose, 2001) by drawing them in to a plot that was not embellished, but which stood out as being typical of many negative autistic experiences of education and independent living.

An opportunity arose in the crafting of his collage for Michael to open discourse around his preferred terminology (Luttrell, 2003, pxiv), as he had already made use of the term 'Aspie' in his narrative (Moran, 2015). This was an important issue, as terminology relates not only to our

identities, but how we are seen in relation to others. For example, whether Michael's reclamation of terminology such as 'Asperger individual' can silence the dominant [outsider] narratives (Smith, 2014), or whether use of this terminology places the individual in a position of dependency based on a medical model of disability (Beardon et al., 2009; Milton and Moon, 2012; Ridout et al., 2011).

My involvement in the evaluation of the support service may have had the unfortunate effect of skewing Michael's perception of me and impacting on information provided. However, as I was able to triangulate data and to meet Michael in a couple of different settings, these led me to form the opinion that he was keen on accessing support, was clear on ways that would be constructive, and that given support, he could build a more independent lifestyle characterised by wellbeing as opposed to distress (Tew, 2015). The outsider narrative layer provided by his mother implied a different type of support to that storied by Michael, focusing more on his challenges. My view of this is that whilst parental narratives are important as a layer in informing the context and influences on an individual's background, progress often demands that past struggles are shaken off, and this requires that obstacles to this, including restrictive terminology, be tackled and discussed (Ryan and Runswick Cole, 2009). So the autistic focus, although storying past challenges, moves towards resolutions, which is different to the 'outsider' narrative. In the wider picture, I consider it of importance to acknowledge both as they work

together to provide possible solutions as opposed to establishing a discourse with a focus that is possibly 'not right' or productive (Brook, 2014).

By contextualising Michael's narrative, it was possible for me to understand how a relatively small amount of focused support could help him turn his life around. Being part of a support group and also using terminology that he owned and felt comfortable with was a massive turning point, supporting the view of other autistics (Graby, 2012). The impact for Michael in terms of his independence and wellbeing, and for service providers in terms of costs, was a message that came through in each layer of his narrative. Devoid of context, these small steps to what amount to enormous progress could have been missed by me as the evaluator, by service providers or funders. CDA permits tackling the position of power within a narrative such that outside influences on Michael can be held to account for his distress, and within an autism friendly context, he was able to express himself and explain indirectly how these impacted on him by stating his expectations of a supportive environment.

As expressed by other researchers in the field of autism, contextualisation of experiences is under-developed (Bracher, 2013), and even when Michael has more control over the storying of his experiences, I am left

wondering as to the origin of his expectations. These may have emerged as a result of discourse with family, his support worker or others at the support group. Michael may even have belonged to online forums and broadened his vocabulary around autism as a result. These matters were there to be investigated further so that his fluid identities can be recognised as intertwined with a diversity of contexts.

Summary

Michael's narratives show some similarities and differences to those of Sophie, but as an older adult he demonstrated the impact of time to reflect on his experiences. These latter fit in with the views of many other autistics, and have much to offer the field of service development.

I now discuss my third case study.

Making sense of Peter's authoring

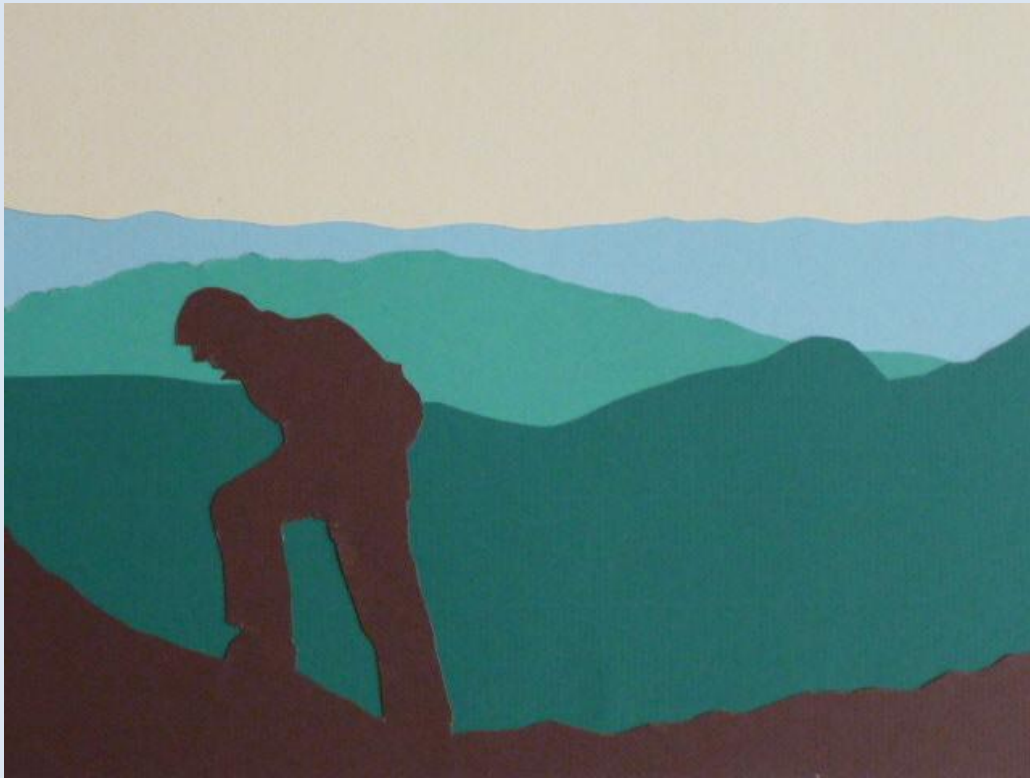


Figure 158: Double hermeneutics and Peter's narrative

In making sense of Peter's narrative, I visualised him as someone who had many talents and skills, and who was able, given support, to climb to greater heights and improve his quality of life. His interests demonstrated a preference for a stepped approach to activities, and this was certainly something he could offer employers. The discussion of his narrative now follows.

Feelings and thoughts

Peter's mind map was surprising in his focus on his skills and abilities and features that outsiders would need to know to make an environment or activity inclusive.

Communication

In expressing his communication preferences, Peter may have been referring to his preferences both for expressing himself and to receiving information (Arnold, 2013), and this information is essential to determine by those working to address his support requirements and establish inclusive opportunities for him.

His communication was mainly performative or written, but there was no doubt that he had a lot to say. By adopting an IPA approach and looking at clusters of words that Peter hung together, it was noticeable that following the initial list constructed in answer to my questions through joint reflection, he then formed another list. This seemed to convey a key message regarding how he and I had just been communicating and/or why the named activities worked for him.

Silence

Silence was something that Peter appeared to use to process information and to communicate (aspie rhetor, 2015), and for him it was a powerful tool as he accompanied verbal silence with physical 'noisiness'. This

mismatch again reflected a sense of dis-ease, which made me wonder as to its origin. However, as with Sophie and Michael (discussed above) the importance of visuals for Peter was critical in re-establishing the narrative agenda and in explaining his experiences (Lawson, 2011). Without visuals at this stage of working with me, our communication would have been problematic as it did not address his support requirements.

Despite his apparent discomfort with the environment, I felt that Peter was keen to engage with me as an audience (Riessman, 2008). As with Sophie and Michael he storied challenges in addition to solutions, and this was in contrast to the dominant narrative offered by outsider narratives. These latter addressed a normative agenda of steps towards independence and success, which fails to recognise the real lives of autistic people (Waltz, 2005b). Peter's data is an illustration of the position taken by many autistic activists, namely that the skills of many autistic individuals are ignored (Arnold, 2012; Simone, 2014). Given the legislation about the rights and inclusion of autistic people (HMSO, 2010; 2014; UNCRPD, 2006), Peter's data, showing clear ideas as to how to resolve some challenges, is useful for funders and service providers. This would enable funding to be utilised more efficiently by addressing individual preferences.

Peter was able to use one of the methods offered to instruct as well as to convey information, and in this way, he maximised his opportunity to

engage with me just for that evening. I was informed about his processing of information via text, and his additional performative narrative advised me about the effect the environment was having on him. There was no sense that he was setting himself against a normative agenda, with any feeling of difference, but that it was a part of the storyline that he required certain facets of communication to be in place.

As Peter only used the mind map part of the collage process, I was unable to ascertain whether he was taking advantage of the opportunity to re-tell his tale, keeping it on the agenda as an issue to be discussed and addressed, or offering some new information. The emphasising role of the performative element, however, served to fore-front what is often an under-represented narrative in relation to autistic people – that of skills as opposed to dysfunction. The ad hocery in methods that I have alluded to earlier (Thomas, 2007b) enabled Peter to seize the moment to show in his diversity of communicative ways his own priority. The need for methods to be flexible was apparent.

Identity and wellbeing

Counternarrative

Peter's narrative of someone with skills, as storied in his mind map, ran as a counternarrative to his performative narrative, where he presented himself as almost unable to engage in a task. The existence of these

alternative stories in relation to intersectionality are mentioned by Plummer (2014), as the former challenges the latter. However, Peter's data demonstrates, as argued earlier (Chapter 2.1), how autistic people can and do work to overcome the effects of sensory overload (Isaacs, 2014b; Williams, 1999b), and this is important for service providers to recognise. If outsiders fail to engage with autistic people to explore the reasons underpinning certain thoughts, feelings, identities and behaviours, the dominant narrative can be skewed such that it does not represent the perspective of autistic individuals (Brook, 2014; Dunn, 2014a). This also supports and links with the argument that I agree with (due to its relevance to this study) proposed by Riessman (2008, p24), which states that 'a failure to share temporal ordering has led to confusion'. As such, this may lead to assumptions by non-autistic people.

Peter's narrative challenges the dominant outsider narrative in that his array of skills and interests portray a diversity increasingly embedded in autistic narratives (Harris, 2015). His challenge to the identity encasement of autistic is direct in that it does not refer to it. In fact, this reflects the argument posed by Bornstein (2013), that polarities are limiting and a threat to opportunity. Whilst at no point does his text refer directly to issues of wellbeing, Peter's performative narrative does provide me with a sense of this. Consequently, I am able to determine that he possibly experiences both low hedonic and eudaemonic wellbeing as

stated by the NEF (2012), but as with both Sophie and Michael, these are likely to cover a wider agenda.

Skills and identity

Placing the autistic voice to the fore in my study was really important, and Peter demonstrated that he could take the opportunity to speak as the expert in his own life to refocus the narrative (Ne'eman, 2010). If listened to, his potential to contribute to society could be realised, but the compartmentalising of autistic people in terms of their perceived ability would have resulted in little or no attention being directed to the environment, and Peter would continue to be denied opportunities (Wallis, 2012).

Despite the fact that his behaviour might suggest that he struggles to be part of a group or even to focus his attention, Peter seized the opportunity to present himself in a very different light. This fits with experiences expressed by others (ARGH and HUG, 2011; Beardon et al., 2009; Worton, 2008). Whilst his data was insufficient at this stage to inform me as to whether he already participated in these activities, or whether they were interests or future hopes, they paint a picture of a talented man. Certainly by the end of the evening, I was confident that the ambient environment and engaging in a new activity (perhaps not explained by me in a way that suited him best) were factors that could be

very disabling for Peter. The results that came from Peter's narrative were unexpected in that he storied so many skills so quickly and provided explanations as to how these suited him. Essentially his story was one of difference, not disorder (O'Neil, 2008), dismissing the prevailing and unwelcome outsider narrative.

Of the three autistic authors, Peter was the one who chose not to mention his autistic identity. This may have been for a number of reasons: an assumed mutual understanding as to why he was at the support group in the first place; he had not completed the collage process, and may have added this information at a later stage, as did both Sophie and Michael in their collage; or it may have been of more importance to Peter's narrative that his identity as a skilled individual was finally heard. This is the story that is so frequently ignored despite evidence to the contrary (Silberman, 2015a).

Frequently, conversation about autistic people talks of 'an obsessive interest', and I feel that this is often devoid of relevant context. Peter's data demonstrated, with a minimal amount of information, that the array of skills and interests he has share some characteristics, but draw on an entirely separate range of skills. In addition, they require him to be able to function efficiently in a diversity of environments.

Outsider negative assumptions, pathologising autism, fail to recognise other identities and abilities (Chown and Beavan, 2012), and it was evident to me as audience to Peter's storying that this probably characterised his current life. With Peter identifying as someone with a number of skills/interests, a lack of data did not enable me to ascertain how life events had changed him (Strauss, 1959 in Hackstaff, 2012). This was an excellent example of how the relocation of power can lead to the recognition of fluid identities.

Participation

Exclusion of individuals from participating in research is an ongoing issue, and one which was raised by the Theorising Autism Project (TAP, 2014). As I have alluded to earlier in the study, people such as Peter, who demonstrate what may be interpreted as distress, may more readily be excluded as it is an easier option than discovering the reasons behind this (Moran, 2015; Simons, 1995). However, taking time to explore ways to work with Peter, and allowing him time to engage with the process, resulted in him not only being able to participate, but to impart a wealth of information absolutely critical to establishing relevant services.

Inclusion should reflect the diversity of autistic people, their communication preferences, and their access requirements (Graby, 2012; Murray et al., 2005), but the set-up of the support group Peter attended

was lacking in its capacity to address this either environmentally or in relation to time. For this reason, Peter was unable to continue his artwork. In terms of Peter's wellbeing, I was able to see how a contextualised narrative allowed me to comprehend issues impacting on him, and which had immediate and adverse effects on his identity (Luttrell, 2012). Rather than being seen as a competent individual, environmental issues could lead to his being seen as dysfunctional. This would more likely lead to his exclusion from projects, activities and employment leading to a lifestyle characterised by distress and a reliance on benefits (Beardon and Worton, 2011).

Context and power

As a theme raised in my literature review, I considered the concept proposed by van Dijk (2008), which raised the question as to whether [autistic] individuals are more able to influence and shape discourse if placed in positions of increased power. This is also raised by autistic people themselves (Brook, 2014; Graby, 2012; Milton, 2013). It is interesting in the context of this study that Peter chose to reframe his experiences by focusing on skills and interests, all of which, whilst essentially different, had a structure that absorbed other themes storied. So Peter's narrative if decontextualised, essentially did not frame autism, but emphasized the skills and interests held by him as a young adult. However, as a dominant narrative, Peter's effectively silenced other

stories (Smith, 2014), which frame the autistic individual as dysfunctional.

Unlike with Sophie's and Michael's narratives, Peter's had no data providing a narrative layer from non-autistic outsiders. This may have been advantageous as the plot was not immediately skewed against him. However, in being absent, on the surface there seemed to be less opportunity to draw Peter into diverse discourse around the views, terminology and attitudes of others that may impact on him. Despite this, Peter's narrative had a clear focus: to story skills and interests and in so doing it provided an excellent example of how refocusing can uncover perhaps unexpected discourse opportunities.

That Peter was unable to finish storying his experiences was a huge disappointment to me, and I imagined it may have been for him as he had been eager to participate. My personal work shows that funding is an issue that impacts on the participation of disabled people in activities and events (Ridout, 2014d; TAP, 2014). This said, the value of using a combination of methods to address this is, therefore, beneficial and borne out by this data. A more flexible approach enabled Peter to participate, and I feel that the continuation of his narrative would have yielded further information invaluable to service providers about set-ups that he enjoys and which enable him to work to his best.

Enabling environments

I am of the belief that a misunderstanding about the impact of certain environments on individuals underpins and leads to numerous misconceptions about both their abilities and personality, and this is in line with the view of other researchers in this field (Beardon and Worton, 2011; Milton and Moon, 2012). When provided with an opportunity that was accessible, Peter may have felt more encouraged to stay involved with the activity. Again, the discrepancy between Peter's performative narrative and his mind map was such that an individual not audience to both would miss data. So the contextualising of his narrative was extremely important to an audience understanding the disabling impact of certain environments on him, as an audience brings with them their own knowledge and ways of perception (Rose, 2001, p30).

A further problem is how as individuals we deal with the distress or discomfort of others. I believe this draws on the notions of empathy and a desire to see people as individuals as opposed to labelling and compartmentalising them, and this is a view expressed by the autistic researcher Milton (2012a). For service providers, if assumptions inform decision-making processes as opposed to a process of meaningful engagement, services are unlikely to be relevant, inclusive or cost effective. This can exacerbate distress due to a lack of understanding of autism and individual autistic experiences (Baggs, 2003; Connor, 2013).

On the night I attended the support group to run the collage workshop, the sites of meaning making in the narrative I tell about Peter mention several key turning points. In meeting a new challenge with someone he had not previously met, Peter demonstrated both action and relational turning points at play, and the value of this is critical as it reinforces Peter's position. He does possess skills and abilities and is able to engage in new activities. So often autistic people who experience the overwhelming sensations of sensory and social overload are either unable to participate, have to remove themselves from a situation (Sequenzia, 2012), or are removed/excluded by others (Carlile, 2011). Peter rose to the occasion to voice his experiences, a moment that should be recognised for its potential influence in transforming the experiences of autistic people.

Contextualisation

Initial deliberation as to whether Peter's perception of me as an evaluator of the support service might have placed me in a situation whereby he felt obliged only to offer positive comments, were quickly dispelled. His storyline was assertive and succinct, and offered me and any service provider a clear way forward regarding elements to address. This is where Critical Realism has a part to play (van Dijk, 2008, p2), as in listening to the autistic voice there is an opening to tackle power and recognise the influence of context on the narrative.

In being an immediate audience to Peter's narrative, I had shortened the distance between the voicing of his experience and my interpretation of it, thereby tackling possible distortion (Beresford and Boxall, 2013, p11). In addition, in contextualising his narrative, I was able to address a gap in research. His data was in the form of his mind map and in the performative nature of his narrative, which initially seemed to be at odds to this. However, acknowledgement of this apparent discord is an essential feature of my study as it again demonstrates how the misrepresentation of autistic individuals frequently occurs as a direct result of decontextualising experience.

Context is an essential part of a narrative (Phoenix, 2008, p72-87), since without it I would have missed out on three key features to Peter's story. First, the impact of sensory and social overload, which enable me to better understand his ability to engage in an activity; second, his determination to be heard when given communication tools that reflected his preferences; and third, that one of his identities is that he is autistic. The gatekeeping issue that I have discussed at several points in my study, and the lack of available venues, meant that it was difficult to address the support requirements of autistic people during my workshop in terms of sensory and social overload. This contextualisation of Peter's narrative enabled me to see the dissimilar themes evidence by his performative and written genres. Furthermore, the similar themes of his

mind map, where the 'rules and strategies make things work' was reflected in the activities named.

The contextualising of Peter's narrative list offered information that, if I were a potential employer, would allow me to more readily tap into his skills. Combined with a clear outline of what environments are enabling for him, adjustments could be made within a job interview process to enable Peter to utilise his skills in a way that would improve his employment success and quality of life. Silberman (2015a) has discussed how on so many occasions autistic people are prevented from contributing to society, and this is in the presence of knowledge that many inventions emanated from autistic inventors themselves.

Decontextualised, Peter's narrative would have been incoherent. The ambient environment and the fact that he was attending a support group for autistic adults were important parts of establishing the narrative scene. This allowed a refocusing of the story such that it then became comprehensible (Phoenix, 2012, p73). This made me reflect on the times that service providers do not have or make sufficient time to understand the information provided, and as a result cuts are made or a badly shaped service is established.

In contributing to a wider narrative, Peter's story could inform the nature and content of a support group and other key groups such as services. With assistance to deal with sensory and social overload, power can be relocated to a position where an individual is able to be independent as opposed to reliant on support.

Summary

Having looked at how I have made sense of Peter's narratives and the narratives of the other autistic authors, it is relevant to consider whether these stories are new or old within the bigger picture of autism.

7.3 Stories New or Old

Arriving at my responses in relation to my research questions required me to use my different sites of meaning making, and to place these within my theoretical framework. This process is a new contribution to the field of autism research, but one which I argue is invaluable as it allows those willing and ready to listen to engage in discourse with autistic people at any point of the narrative process to establish the meaning behind their experiences.

My findings differ from those of many others in that:

1. they place the voice of autistic people to the fore, as highlighted by autistic people themselves (Arnold, 2013; Autscape, 2014; Brook, 2014; Graby, 2012; Milton and Bracher, 2013; TAP, 2014).

2. they allow autistic authors to engage in methods which can be adapted to suit communication preferences (Isaacs, 2014b; Milton, 2013; TAP, 2014).
3. they allow the listener to engage with different sites of meaning making, as one does when visiting an art gallery or creative writing workshop (Brook, 2014).
4. the methodology allows both the telling of new stories, and the listening to ones which have been told many times, but which may have not yet attracted an audience (Andrews, 2014; Moxon, 2006; Murray, 2006a; Ridout et al., 2011).

What has changed over the years is the manner in which autism is represented within the DSM (Chapter 2.2), and the introduction of autism specific legislation, which came into force at the start of my PhD study. The impact of the two is that the first medicalises and seeks to divide a vulnerable and marginalised community, which is beginning to express its voice. However, the second aims to involve autistic people in issues impacting on their lives. Despite this, the inclusion of the autistic voice in research and in shaping services is very limited, as my findings indicate, and the experiences of the autistic authors in my study reflect what contemporary autistic speakers are saying, that services still do not engage with autistic people (Brook, 2014; Dunn, 2014b). As such, there is no recognition of the real lives of autistic people (Waltz, 2005a) or a break from the dependency narrative as reflected in the 'Nothing about us without us' slogan (ASAN, 2014). My evidence supported the feeling

expressed by many other autistics, that the location of the autistic voice remains such that it is not listened to and is frequently controlled by outsiders (Milton and Bracher, 2013).

Adopting a creative approach to the development of meaningful methods of communication is one way of bringing diverse groups together. Regarding my study, which began with the evaluation of a support service for autistic adults, this meant providing an opportunity for autistic and non-autistic people, parents, support workers and service providers to come together in order to discuss service provision (Ridout et al., 2011). It enabled the autistic authors in my study and their parents and support workers to raise themes which could then be discussed further.

Many new stories, such as those illustrated by Michael's collage, focus on neurodiversity; this shifts attention to a more inclusive agenda recognising natural human diversity and away from a focus on being viewed as odd. This is a conversation of more current interest and relevance to many autistic individuals (ARM, 2010; Graby, 2015) than debate which focuses on dysfunction and a lack of skills (Baron-Cohen, 2000; 2008). Furthermore, my findings, discussions with friends and family, and my own personal experiences have emphasised that the feeling of 'being odd' or 'different', as reflected in a medical model perspective, causes a huge amount of distress (Murray, 2006a). This still

is evident in current systems such as DLA/PIP (Disability Living Allowance/Personal Independence Payment) applications requiring autistics to focus on their 'dysfunctions' in order to obtain required support. This process, which should respect a legal right to support (HMSO, 2009; 2014; UNCRPD, 2006), often leaves individuals feeling more disabled as opposed to feeling that they might receive the support to which they are entitled. Ironically, this support would enable applicants, such as Peter and Michael, to contribute to society, thus avoiding a lifetime of dependency on others and would improve their quality of life. The focus needs to be relocated towards addressing social barriers to inclusion, and my data was evidence that attitudes have not changed.

Changes between the past and the present inevitably influence stories told, and this is a point emphasised by Andrews (2013). Those from the past were perhaps more based on the medical model of disability without a counter-narrative being told (Silberman, 2015b), whilst current narratives increasingly include the perspectives of autistic authors, yet still point to institutionalised attitudes and systemic barriers to inclusion (Milton and Bracher, 2013). In my role as a mentor supporting autistic people over many years, and whilst carrying out this research, I have often come across the issue of the role that language plays in enabling or disabling discourse (Graby, 2012; Sinclair, 2012). For example, using the 'accepted language' can be a challenge in itself as regards becoming part

of a community. Whilst the issue of language was not explored in depth, I have noted throughout Chapters 5 and 6 the individual use of autism-related language.

In producing new stories, the concept of co-production discussed earlier (Chapter 2.5) reflects on whether challenges to power are welcomed by all involved, since this has been argued not to be the case (Carr, 2007). In fact, as with the case of other minority groups, many people are not always so ready to accept those who are 'in some way different' (Crenshaw, 1989; Crenshaw, 1991; Reeve, 2015; Runswick-Cole, 2014). This results in discrimination and exclusion, which are so often embedded in fear of 'the unknown'. So can there ever be a situation where autism knowledge production is co-produced? My personal view is that there is unlikely to be agreement on this, but as with the views expressed by autistic colleagues (Arnold, 2014b; Brook, 2014), I believe that there is always a need for people to come together and debate the impact of services on individuals. The new stories demonstrate an increase in the number of autistic voices leading this journey, and as with the fight for equality in relation to other minority causes (Milton and Moon, 2012; Reeve, 2002; Reeve, 2004), I feel this is the right route to follow. However, debate among the autistic community does not indicate that a situation of co-production has been achieved, and this is a point argued by Tew (2006) in relation to mental health/wellbeing. Rather, the situation is such that there is much progress to be made.

My methodology allowed the storying of some main themes autistic authors wished to pursue. My purpose was to provide an opportunity for the participants to lead the way, and this organic approach enabled them to choose topics relevant to their real lives rather than being obliged to attend to the agenda set by the service providers (Ridout et al., 2011). This process might be assumed to be cathartic, but I was under the impression that all three found the process of sharing difficult experiences to be a challenging task (Tajfel and Turner, 1979). That all three continued indicated to me that they wanted me to hear their experiences as relayed by them, and that this took priority. This enabled some 'old' stories of anxiety and distress to be narrated, but also included ones around skills and the reframing of autism-related language.

Although its presentation was slightly different, another point that came across in my study was accessibility to resources, their appropriateness and how they are being used. For example, Sophie's narrative indicated anxiety, which may have been in relation to support not being continued; Michael was able to look at how support had enabled him to move to 'a better place' and 'have a foot in the door of resources', which he seemed to see as a more permanent feature of his life; and Peter used the opportunity to link possible support with employment and skills (Ridout et al., 2011). This could lead to a questioning of the way in which support was being offered by a regional service provider, and can be linked to

arguments put forward by autistic speakers and writers regarding their involvement (Milton, 2011b; Moon, 2014c).

Inclusion of the perspectives of the two parents was important to my study, as it allowed for the introduction of the diverse agendas as set by terminology and attitude and storylines of each author concerned. This provides a wider range of sites of meaning making and encourages discourse around conflicting themes, a point stressed by others researching in this field (Lester and Paulus, 2012; Pellicano et al., 2013). In accordance with the voice of autistic activists, this is necessary if meaningful conversations about what constitutes 'appropriate and relevant services', or what constitutes an inclusive service, are to take place (Brook, 2014). This also concerns attendance at conferences, which many autistic people find difficult due to the financial implications (TAP, 2014), and this further silences the autistic voice. Therefore, it is necessary to engage with the real lives of autistic people to scrutinise how practice can be delimiting or open up opportunities.

The prevalence of autism has not changed (Silberman, 2015b), but the way we acknowledge it has, and autistic/neurodivergent people need to be included. The narratives of autistic authors are addressing both new and old themes, and there is still a requirement for change for the better,

alongside the need to have skills valued and support provided in relevant areas.

Lack of engagement

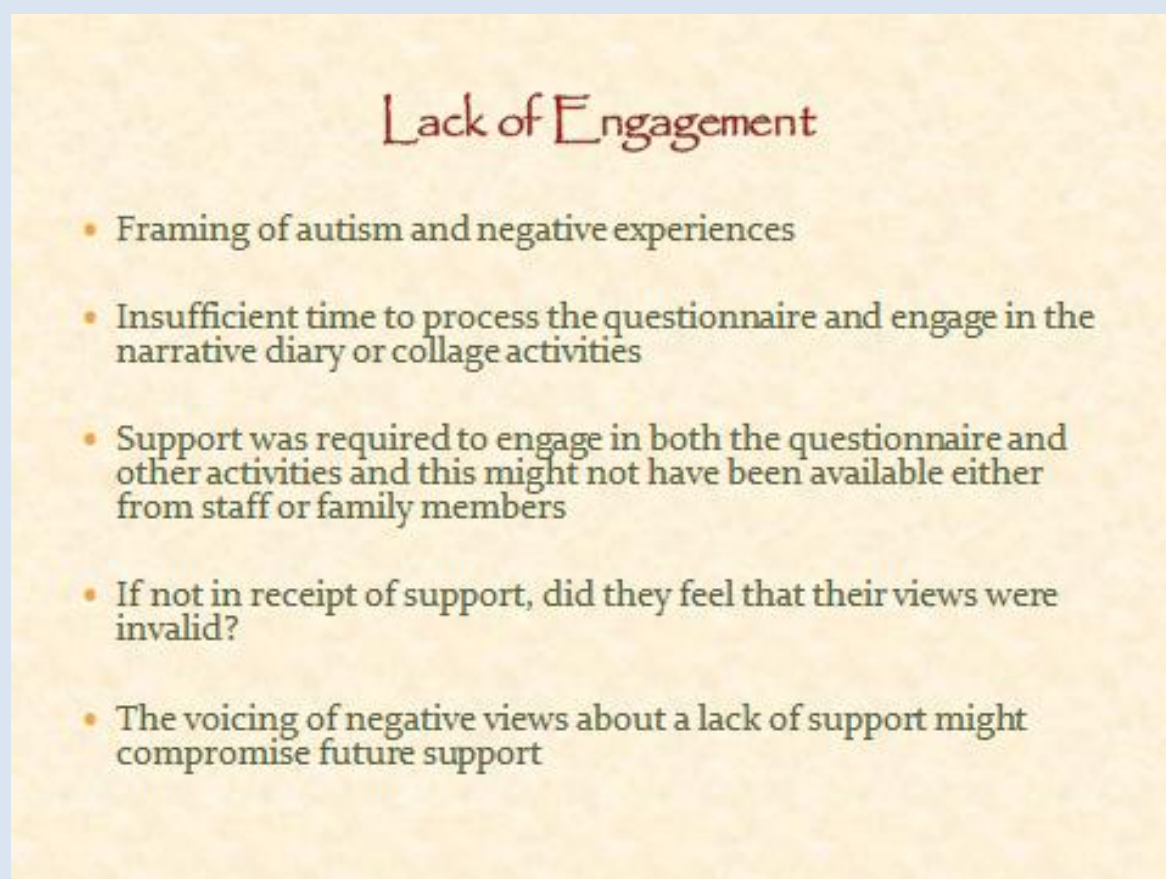


Figure 159: Lack of engagement (author's summary)

A key gap revealed by both narrative genres was that autistic people contacted, who were NOT in receipt of support from Adult Social Care, did not choose to voice their experiences. This lack of engagement may have materialised for a variety of reasons, and particularly due to previous negative experiences around the framing of autism (Beardon and Worton, 2011). In addition, they may have felt that their views were not valid, or

confused as to their exact involvement in the study. However, as missing data, it is essential to reflect on whether additional narratives would provide a different picture of the situation being studied. This is a critical factor impacting on service provision and funding allocations, and I argue that this lack of engagement warrants urgent consideration if services are to be relevant.

Insufficient time or support to engage with the questionnaire process that provided opportunity to do the photomontage and narrative diary, would have excluded people from this study. I believe this to be a critical piece of information for service providers, as the response rate and reasons underpinning it are as informative as other feedback.

Perhaps of most importance in giving feedback about a support service which you depend on is the worry that it will be withdrawn if anything negative is said. This paradox underpins much of the service provision in this country as insufficient time is given to carry out this essential piece of work effectively. Attention to this is a priority if the situation is to be improved.

7.4 Untold Stories

Because the Story is not told, does not
mean that it is not there

- Imposed time frame
- There are always more stories
- Engaging with the abstract is harder and requires more time
- Building of trust

Among the different narratives both across and between data sets, there were many untold stories where themes were introduced. In addition, there were stories which were either not remembered or introduced. For example, Sophie introduced unexplored themes of friendships, a relationship and a desire for change, which were raised in the earlier parts of the collage process. However, these are not the only untold stories, as she refers to problems researching and sudden changes, about which she does not elaborate, and this could be viewed by an audience as a situation where there is missing information. Michael's story of his

independent living situation was one that was not followed through in his data, yet was introduced by both him and his mother. In addition, he did not explore the themes of employment or education, his skills or interests, and I was unable to gain an impression as to how he had reflected on the strategies he had established in the past, which had not served him well. Peter, on the other hand introduces themes of skills or interests, but again does not follow these through. Nor does he story whether he is living independently, and there is no insight into any existing social situations.

The issue of disclosure often arises as it defines 'in group' or 'out group' membership (ANI, 2000; Bagatell, 2007; Chown and Beavan, 2012; Graby, 2012) and extends discourse into the area of who has a right to define these boundaries. The advantage and purpose of disclosure and its closely related issues of diagnosis and self-diagnosis are political matters, which were not explored in any depth by the autistic individuals in my study. Nevertheless, these issues require constant attention to ensure that inclusion is addressed. Furthermore, the recognition of skills, such as those storied by Peter, are then more likely to become a prominent theme as opposed to a surprise that autistic people have any skills in the first place, or conversely, that they are extremely gifted. As with other matters such as gender, sexual orientation, race, this polarising of autism does not help the debate, but is further delimiting (Perry, 2014).

Absence of a certain story does not suggest that characteristics of the normative narrative do not form part of the autistic narrative. Although it is not necessarily the case that they do, merely it is evident that they were not storied during the study timeframe (Phoenix, 2014). Perhaps this is indicative of a difference in priority. Certainly the future was being thought about, and the bigger narrative provided by combining all the data sets of individuals provides diverse experiential perspectives. These in turn may encourage an audience to question the relevance of support themes being addressed by service providers. An example of this application may be discussing ways to reduce anxiety as expressed by individuals, or discussing the use of a more practically oriented theme. It is, of course, possible that a combination of the two would provide better outcomes in terms of assisting individuals attain their life goals. The collage provided a versatile method which could be adapted and manipulated from week to week, so thoughts could be arranged and re-arranged visually whilst engaging in discourse with others or by listening to discourse and reacting to this through collage.

It was apparent during this study that use of visual imagery assists the imagination by tapping into creative skills, prompting thoughts and discussion, and use of textual images can contribute ideas (Robinson, 2010; Robinson, 2006b). As such, the construction of a new narrative about the future is plausible. Fresh possibilities can be opened up, and as Sophie demonstrated, she is eminently able to include and develop the

ideas of others as and when she feels necessary. Perhaps Michael has a clear idea of the future he would like to story, and one that goes beyond his support at the group. And Peter, developing his chosen media, may have been able to provide more insight into his story of what he would like from his future. He mentioned several activities and interests, and these provided invaluable openings to potential employers or educators in terms of exploring and discussing opportunities with him so that he might contribute his skills to his chosen area. The images provided by Sophie, Michael and Peter attend to the experiences they wished to story given the available time. As evidenced by data across all three individuals and data sets, there are plenty of narratives ripe to explore. However, acknowledgement that just because I had indicated my willingness to listen, did not signify that autistic authors were ready to tell (Luttrell, 2003, p164). Although I was concerned that authors would not be able to engage with the activities, I am certain that the informing of my methods by autistic people contributed to a positive result.

The narratives of the autistic authors were generally based in the here and now, with any attention to the past introduced as part of the explanation as to 'how I ended up where I am today'. For each, past experiences had clearly had an impact on their lives, yet they were more eager to focus on being able to address issues to enable participation and inclusion now as a step to future goals. These might involve exploring the employment process in manageable steps such as: identifying skills and

interests; looking for employers; the application process; the interview process; and how working with others could establish proactive systems where reasonable adjustments become the norm. These stories were untold.

The ending of the evaluation which fed into this PhD study was unsatisfactory for a number of reasons. The ultimate position of power is when funding bodies choose to engage in situations with [autistic] people, access their views, and to 'walk away'. The pressures on staff were apparent as there had been significant pressure on them to encourage autistic people to give feedback about their support service. Due to staffing changes throughout this period, it became difficult for me to return to disseminate the evaluation report or gain feedback. This had been envisaged as a critical part of the evaluation process. In addition, I was unable, due to reasons of access, to return the work that autistic artists had crafted, and which had been framed, due to staff pressures. However, I was able to attend two meetings to present the findings and run workshops with staff on the ground, although it was very telling that senior management left prior to these and refused to talk. I found this to be really disempowering as I had planned to discuss opportunities for displaying the collages produced and perhaps linking these with other workshops that the autistic people themselves might like to run.

The end result was an evaluation of a support service informed by autistic voices (Ridout et al., 2011), but dissatisfaction on my part that there had

been no opportunity to discuss findings and disseminate the report as planned. As part of a piece of research narrative, the beginning, the middle and the ending are all important. Perhaps the fact that the ending did not happen in the way envisaged is a reminder that these events cannot always be controlled, but that there may be future opportunities to re-enter a narrative and pursue another storyline. This is the message for service providers...there is always another opportunity to re-engage.

Chapter 8: Conclusions and Suggestions for Future Research

This study explored the experiences of three autistic individuals using diverse communication preferences used to evaluate a support service (Ridout et al., 2011).

I began with a discussion of my overarching meta question concerning involvement of the autistic voice in service provision, to link my study with the service evaluation as it was critical to acknowledge the origin of my data. I highlighted that the majority of autism research fails to involve autistic people at any level other than that of the observed participant (NAS and Ask Autism, 2014; Parsons et al., 2009). I then familiarised readers with the relevant legislation impacting on this field and the range of theories and models of disability that inform both theory and practice. Finally, I introduced and discussed the key themes of identity, wellbeing, context and power as these had emerged from the evaluation of the support service and had informed my research questions.

Placing the Autistic Voice as the Expert Insider Voice

The specific area of interest for my thesis emerged as I became aware that critical data from this type of service evaluation is frequently overlooked, under-valued and ignored by researchers, practitioners and

service providers. The reason I believe that this happens is that certain methods are valued over others. Yet with autistic people, these methods, and the methodological approach concerned are those that would work towards improved participatory processes and inclusivity. I have argued that recognition of this data as a resource for exploration would better inform services, policy and practice. My findings have also indicated that this practice extends to other services, such as those specifically related to mental wellbeing.

IPA and double hermeneutics

‘...ultimately we must be willing to take seriously that the way we see the world is only one way amongst infinite possibilities, to recognise the situatedness of knowledge and of interpretation.’

Andrews (2014, p27)

In listening to the voice of autistics and how they make sense of their experiences, there needs to be an opportunity to acknowledge a range of

diverse identities other than 'just autistic.' The stigmatising of autistic people by assuming that there is a general understanding of what 'being autistic' means has a devastating impact on the wellbeing of many autistic people (Andrews, 2006; Beardon and Worton, 2011). True engagement means finding out what it is that the individual has to say for themselves. This leads to an understanding of the real identities that each individual wishes to be recognised, and the skills that they have to offer or would like to develop. I believe that this calls for a transparency within the research process, which allows readers to understand diverse interpretations available. This means not only offering a range of possible interpretations to be considered, but also being clear about what you, as a researcher, bring to the research process.

A consequence of an agenda skewed towards the priorities of non-autistic individuals is that the wrong conversations between autistic people and service providers are established from the beginning (Brook, 2014). Therefore, in considering my positionality on autism, I focused on the factors that were important to autistic individuals (Ridout et al., 2011). As someone who is herself neurodivergent, I was working from a basis of insider-curious outsider expertise, and I wanted to be able to encourage this diversity of narratives. However, at this point, I realised that there was a gap in methodological approaches in the field of autism research that would allow me to address the concerns of the three individuals that had been selected. For this reason, I decided that my study focus needed

to be on developing a methodology that would acknowledge the priorities of the expert insider voice, the autistic people themselves, and facilitate an exploration of their priorities.

This was a key step in my decision-making around understanding how autistics were making sense of their experiences, since evidence from my study was indicating in one area at least, wellbeing, that the autistic agenda is much more nuanced and less prescriptive than that expressed by outsiders (NEF, 2012). I would point out that the questionnaire method may not always be the preferred method for autistic individuals to communicate their wellbeing in the first place, unless informed by autistics themselves (ARGH, 2014). This was supported by my data, particularly when Michael more readily moved between his narrative text to the collage to story anxiety, depression and then his expectations from a support group. This was not apparent in the questionnaire used to evaluate the support service he was accessing (Ridout et al., 2011).

Other data, shows how Sophie discards all her images around love and romance to story problems and possible solutions, and whilst her solutions are more detailed in that they include loving her different identities, this provides a tension between data showing her achievements and that highlight her anxiety; Peter's performative anxiety is set against his listed skills/interests; and Michael, is able to demonstrate how, with a little help, he is able to be organised and take

control over his anxiety. All of these experiences fit with explanations provided by other autistic people (ARGH, 2014; ARGH and HUG, 2011). The advantage of my methodology is that it entices the listener to engage further with the expert autistic author to explore experiences in greater depth.

An additional advantage of my framework is that it may act as the first step in a pathway towards transforming experiences, such as those expressed in this study. The reason for this is that it holds at its core an acknowledgement of the multiple perspectives of contributors: autistic individuals, parents and carers, practitioners, researchers, policy makers and service providers. The findings of my study are evidence that the combination of interpretative phenomenology (with power embedded in this), narrative enquiry and critical realism facilitate this process.

Context, enabling environments and location of power

My methodology allowed autistic people, as the expert insider, to introduce the terminology that they wished, and engage with terminology being used about them. In so doing, it provided potential sites for discourse (Brownlow et al., 2006; Luttrell, 2003). Even when endeavouring to engage autistics as participants, many methods, such as questionnaires and interviews, use terminology which is offensive or which does not reflect the identity of the autistic individual (Milton, 2011b; Reeve, 2002). This alone may be sufficient for autistic people to

be discouraged from engaging with research as they feel misunderstood from the outset.

Ownership of terminology used to describe oneself has a profound effect on wellbeing (Andrews, 2006; Luttrell, 2003), and that the three autistic authors chose to express their identities differently was important in reflecting and emphasising the diversity of autistics. Furthermore, my research data support the views being expressed by autistic people, both individually and collectively (Autescape, 2014; NAS and Ask Autism, 2014), that terminology needs to reflect individuality and changes over the lifespan. This would reflect changing identities and priorities. Clarification of the terminology being used by autistic and non-autistic individuals is crucial from the outset, in order to avoid confusion caused by distinct definitions and related agendas (Brook, 2014).

That the methods used in my study were informed by autistic people themselves, recognising challenges and preferences, was a critical step towards inclusivity, by way of creating an enabling environment. As a more welcoming approach, the recognition of the preferred terminology and priorities of participants allowed them to drive their agenda on autism forwards in the direction that they wished. In the case of Sophie, this enabled her to refocus her narrative on anxiety and a desire for change, whilst providing some solutions. Michael introduced terminology such as

'neurotypical' or 'emotional literacy' that suggested he was conversing with autistic communities or people who worked with other autistics.

Different communication styles can place barriers to autistic people participating at any meaningful level (Brook, 2014), and simple responses to this, such as knowing what works best for someone and having a familiar person who knows and understands you, can facilitate the participatory process. In addition, the simple practice of providing information beforehand and time to engage with it enables more autistic people to participate (Lawson, 2011).

Whilst Ne'eman (2010) mentions that the agenda on autism is being steered away from the priorities of autistics, my data illustrates that the autistic agenda is there to be accessed. However, I support the view argued by many autistics, that until autistic people are involved in policy making (Brook, 2014), at all levels of research and service provision (Milton, 2011b), and in the prioritising and delivery of training (Dunn, 2014a; b; Isaacs, 2014a), the situation is unlikely to change.

Context is essential to understanding (Garfinkel, 1967; Mischler, 1979; 1999; Phoenix, 2008), and the fact that autistic people's experiences are being decontextualised means that many live a life characterised by dis-ease and frustration regarding barriers to inclusion (Milton and Moon, 2012; Reeve, 2004; Reeve, 2015) This skews their agenda from wellbeing to that of dysfunction. Data from all three autistic authors showed how

processes, images, audiencing and discourse could either impact positively or negatively on the way in which their experiences were understood by outsiders. For example, people unaware of issues relating to sensory or social sensitivities might fail to understand the opening of Michael's narrative diary regarding education experiences or the impact of these on Peter, who still wished to participate.

Contextualisation of experiences of change are particularly important to understand, and several of Sophie's unexplored themes, placed under headings in the collage process, showed how many issues may remain unaddressed. I would argue that the location of power is particularly important to scrutinise at this point, since autistic people often speak to a different agenda to that of non-autistic outsiders (Brook, 2014). Sophie, as a young teen in transition, produced data that highlighted this point, since the location of power resulted in the introduction of distinct themes, which would have impacted diversely on her wellbeing. As with research with other marginalised groups (Harris and Farrington, 2014), the evidence from my study pointed to the fact that autistic experiences are often misunderstood as a direct result of being decontextualised (Vedeler, 2014), and this results in individuals being unable to engage with services or to contribute their skills to society (Hotham-Gough, 2013).

Another theme worth reflecting on was whether my data could in any way support the argument that autistic people are different to non-autistic

people, and the data definitely pointed to a difference. However, that the emphasis was on difference as opposed to disorder (O'Neil, 2008) was critical as it allowed for the causes and implications of anxiety to be considered and addressed. That extreme anxiety was experienced by the autistic authors was an issue that needed to be viewed in the context of their real life experiences of difference and the real triggers of stress, since without this mental distress can be exacerbated (ARGH, 2014; ARGH and HUG, 2011). Different to the possible narratives of many non-autistic people is that in the time available, autistic authors did not story stories of employment or independent living, but their successes, failures, plans or dreams. Peter was more able than the others to story his skills, but it was necessary to put these in the context of his challenges, as these would not have been apparent to an audience not present at the actual narration. Michael stated clearly that he had expectations of a support group, and it is likely that this theme would expose skills he had to offer, or interests that he would like to explore. Sophie was struggling with themes typical of many teens, yet her stress triggers needed to be further explored as anxiety, as opposed to achievement, was a major theme for her.

Understanding the autistic voice in a context that is not tokenistic is paramount to meaningful engagement.

Methodology and analysis

My methodology involved the exploration and adaptation of methods that were already in existence and adapting these to the requirements of individuals. By essentially combining existing media, I was able to develop a more cost-effective resource for the exploration of under-utilised data, something that has much to offer future researchers. In addition to considering a number of methods to determine their ability to access diverse communication preferences, I considered how I could look at the methods to address my research questions. These focused on the expressed concerns of autistic people (NAS and Ask Autism, 2014), and located both within my study framework. Furthermore, the combination of typologies of analysis is recognised more generally in the field of narrative research as not being mutually exclusive (Riessman, 2008, Chase, 2008, Denzin and Lincoln 2008), and this was also the case with my study enabling the inclusion of data reflecting diverse communication preferences.

As with the work of Luttrell (2003), which had also influenced my methodology, I was able to demonstrate that mixed media readily taps into the communication preferences of individuals. In addition, by utilising a flexible methodology, autistic authors were able to adapt the methods, working and reworking their memories to story their experiences. As someone who was naturally creative, Sophie worked to her strengths and explored textures and styles. In contrast, Michael experimented with a

new art form, and although this provided a challenge, the methodology allowed him to deal with anxieties.

The success of this way of working was apparent in that it drew attention to a diversity of narratives. Although all participants storied anxiety differently, it arose as a common theme. In just one session, Peter was able to tell me how to work with him in a way that was inclusive and would undoubtedly provoke less anxiety, and this was woven between interests. In addition, the range of additional themes introduced in such a short space of time was interesting: expectations from a support group; feelings around support more generally; and the presentation of skills/interests that could be tapped into with attention paid to communication preferences. My data challenges the work of researchers such as Gillott and Standen (2007) by using methods which better reflect communication preferences of autistics. As such, data from autistic narratives shows how issues such as communication (Michael and Peter), a lack of involvement (Michael) and low confidence and a need for change (Sophie) may be suggestive of struggling to fit in and adapt to a normative agenda.

My primary argument here is that scanty resources are being wasted by developing new tools and introducing them ineffectively. Policy and practice in this area needs to change.

Sites of analysis and methods

The sites of analysis that I used throughout my study were important, as they were of particular value to a disenfranchised or hard to reach group. As such, by permitting authors to craft their experiences and to be able to stop this process at any point, as a researcher I was able to value their contribution and include it within one site of meaning making. The following diagram shows how, within the sites of meaning making, aspects of each method were situated:

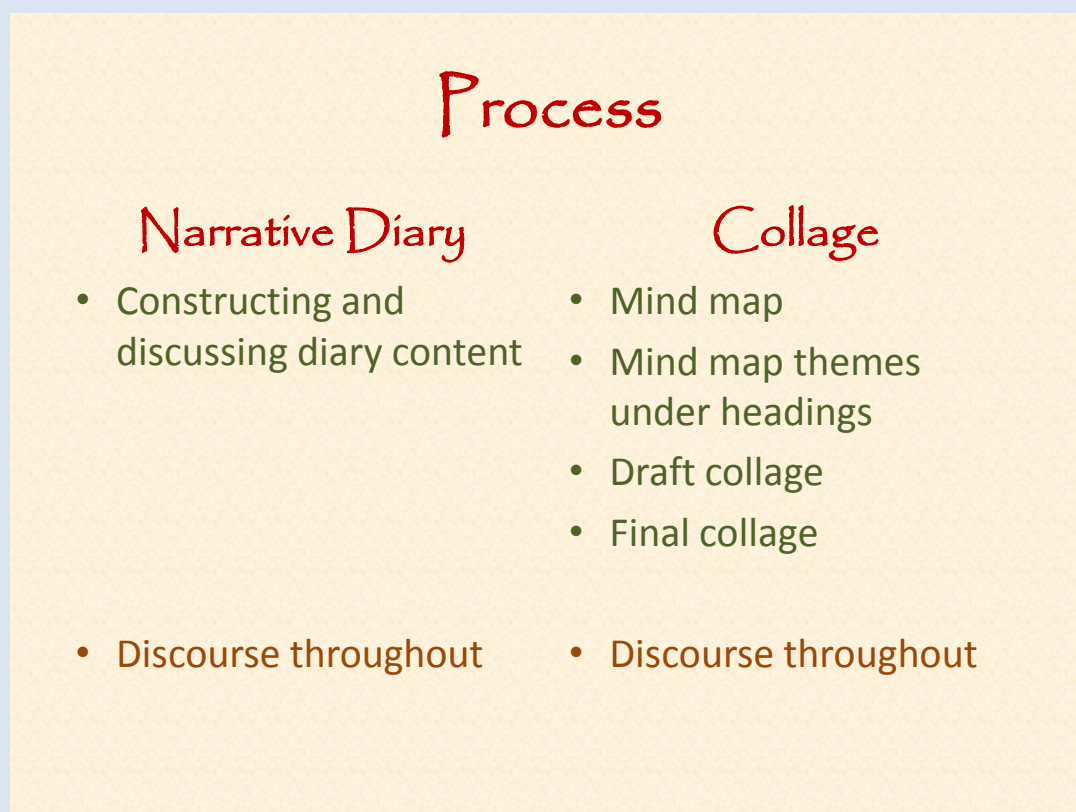


Figure 160: Sites of meaning making – process and methods

There were two methods offered to individuals to further explore their experiences of autism, and within this, there were four points where they could choose to engage or disengage with the process, as illustrated above. This enabled inclusion of 'incomplete' data such as the production

of a list of themes, as evidenced by Peter's data. Throughout any parts of these processes, discourse was a feature, either during or after or both of these, and which may have had an impact. My methods allowed Sophie, Michael and Peter to abandon their paths of certainty (Andrews, 2014 p115) in an exploration of diverse methods to communicate their views and delve variously into their own personal narratives. As such, they allowed themselves to become 'vulnerable to new ways of knowing', as perhaps did the two family members and staff, who also contributed to the different narrative layers. Whilst perhaps not being generalisable as such, the stories told are certainly worthy of comparison and inclusion in the bigger autistic narrative. Maybe in some way they will encourage non-autistic individuals to also make themselves 'vulnerable to new ways of knowing', so engaging with autistics in a meaningful process to develop inclusive services for autistics (TAP, 2014).



Figure 161: Sites of meaning making – image and methods

The second site of analysis involved the actual image produced as shown in the figure above. I was provided with the narratives produced by Michael and Sophie, and for a range of reasons, such as time to familiarise myself with both individuals and their narratives, I decided to let the image speak for itself. For this reason, it was important to endeavour to be transparent in the range of interpretations I offered in my analysis.

My application of the sites of analysis to my data meant that Peter's list was able to be acknowledged as of equal importance as the other images offered. This was a fundamental ingredient in my study, as I wished the

voice of each participant to be heard regardless of how much they wished to contribute. I believe that this site of meaning making demonstrated this point beautifully.

Audiencing	
Narrative Diary	Collage
<ul style="list-style-type: none"> • Sophie's support worker (directly involved) • Sophie's mum • Michael's support worker • Michael's mum • Me • Discourse throughout 	<ul style="list-style-type: none"> • Sophie's support worker (directly involved) • Sophie's mum • Michael's support worker • Michael's mum • Michael's girlfriend • Me • Discourse throughout

Figure 162: Sites of meaning making – audiencing and methods

The audiencing of the narratives told was an interesting element, in that an ability to be able to stand back and reflect on one's influence or engagement with the narrator is essential to the interpretation. In then presenting a range of possible options (as a new narrator) in conjunction with an explanation as to my positionality, I believe it to be more plausible for others to determine the credibility of my interpretations. Factors such as an audience's stance on disability, including terminology, would play a critical role in a narrator's style. Whilst some might become

more determined, and I believe this to have been demonstrated by all of the autistic authors in my study, others might be silenced. My view is that it is the factors relating to context and power that have been woven throughout my study that impact so heavily on this ability to story to specific audiences.

Turning Points	
Narrative Diary	Collage
<ul style="list-style-type: none"> • Sophie's diary showed a tension between successes made with support and anxiety • Discourse throughout • Michael's diary talked the audience through achievements once support was provided 	<ul style="list-style-type: none"> • Sophie decided to discard the majority of the draft collage images to focus on a story around anxiety • Michael was able to demonstrate his clear thinking and expectations • Peter stressed enabling environments • Discourse throughout

Figure 163: Sites of meaning making – turning points and methods

The turning points, unexpected happenings in the storying of experiences, were exciting aspects of my study as they challenged the dominant narratives of autism. A message that resonated through the experiences of all three authors was that being anxious does not imply an inability to engage with others, an ability to live independently or the absence of any skills that would benefit society. Social systems and terminology are

excluding autistics, and contrary to the belief that they are dependent and only capable of 'low key' jobs, they want independence, and there is an extremely wide range of skills reflected among this sector of society (Arnold, 2013; Chown and Beavan, 2012; Milton, 2014d; Silberman, 2015b).

As with the other sites of meaning making, there was room for discourse and to check that the message conveyed was understood correctly. This element is so often lacking, resulting in frustration among many autistic individuals (Brook, 2014).

I now look at the value of my study in the field of autism research.

Relevance of my Study to Services and People's Lives

My study highlights the difference that would be made if these matters were listened to. Autistic people are saying loudly and clearly that they not only want to be involved in informing and shaping services at all levels of this process, but should arguably be leading the debate as this would better inform terminology and priorities (ARGH, 2014; NAS and Ask Autism, 2014). Considering the contribution of many in shaping our current everyday lives (Silberman, 2015b), there is no excuse for this not to happen.

My position is that the increasing amount of autistic narratives should be foremost in informing and shaping the services, particularly of young individuals in transition to adulthood. In addition, autistic adult voices have a role in the way that any other adult has, but the different time required by each to process information is critical to the way in which autistic, neurodivergent and non-autistic individuals communicate. In order to facilitate meaningful processes of engagement, autism friendly environments need to be established, which includes addressing communication preferences, attention to sensory and social processing differences and shifting the location of power by placing the autistic voice as the expert insider voice. Moreover, I am of the belief that if autistic people do not take the lead on this, or are only involved on a participatory level, it is more likely that terminology and agendas will be irrelevant. These need to be those used or prioritised by autistic people themselves. Thus from the outset, autistic people find themselves frustrated and not listened to and working from a point where they are pathologised and medicalised (Milton and Moon, 2012), as opposed to being respected as equal members of a neurodiverse society.

In looking at the lack of involvement of autistic individuals in the development of policy and practice, my study has pointed to several key features, which have been raised by autistics in other situations. Needs assessments such as the Personal Independence Payment (PIP) involve completing a form and generally followed by a standard interview, which

shows no acknowledgement of changes over time. Data such as that contained in Michael's narrative text demonstrates that these assessments need to be carried out over several sessions, using methods which are flexible and which can be adapted according to communication preferences. As such, they would allow all involved to reflect on and process information, adjusting it according to priorities which in themselves may be in a constant state of flux (Pellicano et al., 2013; TAP, 2014). In addition, the timescale for engagement with assessments or application forms is frequently inflexible, and for this reason again, individuals may be unable to access areas such as funding, courses, housing or employment. My data showed that methodology pointed to a need for flexible processes.

The relationship between the assessor and the autistic individual should be on the terms of the autistic person. Without attention to issues such as this, context and power impact negatively on the wellbeing of the autistic individual, and their ability to engage in either an assessment or a service is adversely affected (ARGH, 2014; ARGH and HUG, 2011; NAS and Ask Autism, 2014). One way of doing this would be to send out information prior to an assessment so that the autistic individual can reflect on their support requirements. A more effective communication exchange would then reflect the communication preferences of the autistic individual, and the assessment could be carried out over a period of time as in this study.

This is important as it allows autistic people to remember and to reconstruct their experiences.

Discussion with autistic individuals in my study would have revealed which of the processes, if any, was useful to them, and whether they would have liked to progress this work. Without this information, it is difficult to say whether the best possible method(s) was used, but the fact that individuals were engaging was encouraging. What it did illustrate, was that a combination of media or methods better accessed information critical to informing services.

Another factor impacting greatly on the participation of autistic people in processes informing and shaping the provision of services is economics. This was raised in two critical forums, namely the conference on Participation and Inclusion from the Inside out (NAS and Ask Autism, 2014) and the Theorising Autism Project (TAP, 2014). Many autistic people face discrimination at all stages of the employment process, and for this reason are dependent on benefits. This in turn precludes them from travel to conference venues or payment of conference attendance fees, albeit that they might be reduced. Consequently, they are unable to inform processes that impact on their lives.

My presentation of how the bigger picture of autism could be portrayed by illustrating similarities and differences across data sets allowed me to show that the explicit or implicit impact of services, inappropriately formed services and an absence of services arose as a constant theme

throughout this study. Moreover, it has also arisen in ongoing discussions with autistic friends and colleagues (Arnold, 2013; Autscope, 2014; Dunn, 2014a), and this is further evidence of the real lived experiences of autistic people. This was important in maintaining my focus on the issues relevant to a diversity of individuals.

The evidence from my study and my own view support that of the wider autistic community, that a failure to recognise the differences in terminology and agendas will not allow society to recall that its considerable advances have in many ways been due to the exceptional skills of autistic people, such as in the fields of information technology and engineering (Silberman, 2015b) and art (autisticinnerspace, 2015). The imposed identities and terminology emanating from a medical model of disability are disempowering, and have placed and continue to place significant constraints on the ability of autistic people to contribute to society as they would wish. This is reflected in employment figures (Forsythe et al., 2008; NAO, 2009). Furthermore, it is difficult to acknowledge the potential contributions of people, autistic or non-autistic, if their identities are constantly set against a backdrop of dysfunction.

Whilst I have discussed how potential employers could use the list of skills provided by someone such as Peter to adapt interview situations and work environments, this is also informed by autistics such as Shore (2008) and Simone (2010b). However, I firmly believe that there is a

much more important argument to make, and talking from the perspective of someone who experiences extreme sensory overload, these enabling environments are so often those that are much more conducive to improved work production for everybody. Autistic individuals are diverse, just as non-autistic people, and the views expressed in my study reflected neurodiversity - embracing skills, expectations, communication differences/preferences and a whole range of feelings, but with anxiety prioritised. Adjustments to environments that are better suited to all may well assist in reducing anxiety in the workplace, make better use of resources and embrace our shared neurodiversity.

Future Research

The approach I adopted enabled participants to work individually or collectively, and although each author chose to story their experiences individually, this may reflect the way in which I introduced the task. A future workshop that would be interesting, and which I have already introduced via the Theorising Autism Project (Ridout, 2014c; Ridout, 2014d), would be to explore specific themes collectively.

The flexibility of my methods was set within a more rigid timeframe for the data collection, which was unfortunate, but this was imposed by funding constraints (Ridout et al., 2011). For this reason, there will always be stories that are untold or themes that are not followed. Arguably of more importance is whether autistic individuals are provided

with an opportunity to voice their experiences and to pursue their agenda in effecting change (NAS, 2009; NAS and Ask Autism, 2014; Pellicano et al., 2013). My data has demonstrated that many themes mentioned often go unattended by service providers and support workers due to a range of factors, including time, and this was no less true of my study. These themes comprise a rich resource of future opportunities for authors, researchers and service providers. These should be both acknowledged and addressed, particularly in the current economic climate, as there are considerable benefits to be made for both the autistic individual and society as a whole.

Whilst each method leaves plenty of room for further exploration, the richness of the data accessed through this study was essentially as a direct result of combining narrative genres. For this reason, future studies particularly seem to favour exploration of mixed media. In addition, my study illustrates how creativity can assist in the presentation and understanding of a diversity of perspectives and facilitate innovative resolutions to problems.

Summary

The originality and contribution of my work falls into two key areas:

Methodology and methods development

My main contribution concerned employing a flexible methodology, which allows the diverse communication preferences of autistic individuals to be

valued and included. The areas of both research and the evaluation of services frequently make use of methods that do not acknowledge these preferences, and as a result exclude the valuable contribution of many autistic people. Therefore, the methods chosen were readily accessible, cost-effective, informed by and piloted on autistic individuals, who then provided feedback (Ridout et al., 2011). The feedback from autistic participants in the pilot study was used to ensure adaptability to individual requirements and to inform the development and combination of mixed media for my main study.

My methodology allowed the acknowledgement of communication preferences of a marginalised group, autistic people, who are otherwise exposed to and expected to engage with a singular approach or methods informed by non-autistic individuals. In addition, my methodology was receptive to individuals' need to adapt methods to suit their requirements, and the analysis also permitted acknowledgement of individual experiences. In being adaptable to respond to and embrace the individual requirements of autistics by opening up a range of narrative genres, my methodology and analysis enabled the exploration of expressed autistic experiences, such as skills, that may otherwise not have been heard. This is an original contribution to the field of autism research.

Contribution to the subject area of autistic voice

The contextualisation of narratives was key to relocating power and determining whether the narrative was the authentic autistic voice or influenced and shaped by the non-autistic outsider. Attention to layered narratives and new stories accessed through different media encourages autistic individuals to imagine and work towards new outcomes. Researchers and practitioners need to be mindful of situations where a dominant outsider narrative is being imposed, and particularly through the use of a narrative data sourced through a single medium. My study demonstrated that by contextualising autistic narratives and employing distinct sites of meaning making (process, image, audiencing, turning points and discourse) in their analysis, it is possible to determine more readily where the autistic voice is silenced. This is an important element in establishing appropriate and relevant services and inclusive practice.

The autistic individuals in this study showed without doubt that they were ready, willing and able to explore new ways of expressing themselves and imagining their realities. In order to adopt a more inclusive participatory approach, it is time for non-autistic individuals to welcome and attend to these narratives and to do the same.

Appendix: Pilot Study

Although I aimed at recruiting 4-6 participants, only two were keen to participate, and so the pilot perhaps could more accurately be called a scoping study.

Origins of Selected Methods

My background experience in the arts and education has shown me that the purpose of a method is key to informing its design. An understanding of potential challenges and barriers faced by the participants is critical, particularly when working with vulnerable/disenfranchised individuals, as it facilitates the building of trust. Method adaptability, which facilitates inclusive practice, and a well-structured warm-up or lead-in can be an innovative and enjoyable means of addressing pre-session anxiety and getting to know other participants. So I chose two games which I had successfully used with other young people, and which were popular with my family. Of importance to me was noting which aspects, if any, worked for autistic participants, what could be adapted, and what just did not work.

Pilot Implementation

The pilot was implemented in two parts: a focus group (comprising two warm-ups games and two activities regarding education) and a semi-structured interview. We each wrote our names on sticky labels, and I presented the focus group activities checking understanding by asking one participant to repeat the instructions to the other.

Focus Group/Scoping Study Games

Warm-up 1: participants took it in turn to call out words related to education and to write these on flip chart paper.

Warm-up 2: as above, but each participant had to call out a word related to education that began with the last letter of the word called out beforehand.

Task 1

Participants were asked to write the word 'education' anywhere on a piece of flipchart paper, and to write on post-it notes any words or phrases describing any relevant experiences related to this. The notes were placed around the flipchart, and being removable, I hoped to reduce anxiety if participants worried about 'getting things wrong'. As a creative session, the format aimed to encourage interaction, where ideas mentioned by one participant could be used by the other to prompt their own ideas/memories. Conversation was encouraged throughout.

Task 2

As a more complex development, I asked participants to write questions on post-it notes they would like to be asked about the above experiences to tell service providers how the education service can address the needs of autistic people. These were stuck on another flip chart, and as it was a parallel activity, the questions posed by one individual may have acted as a visual prompt for the other.

Individual Interviews

The focus of these was to explore participants' experiences relating to employment, and to facilitate expression of points significant to them, I made use of prompt cards to help interviewees remain on topic, namely 'employed', 'unemployed' and 'previously employed but now unemployed'. These would be used if necessary in accordance with their current work status. With each individual I explained my interest in the questions they felt important to be asked in order to inform service providers about their needs. I explained service providers to mean any organisation or person involved with helping individuals access and maintain employment. The participants had both been employed, but were now unemployed so prompt cards were used to assist their voicing of support required and given (a) **before**, (b) **during** and (c) **after** employment.

Feedback and Learning Points Informing Main Study

- the games establish a relaxed and focused atmosphere;
- forming questions was difficult and drawing would facilitate this;
- methods chosen needed to be adaptable to individuals' needs to maximise opportunity for engagement;
- visual methods were preferable and could be combined with other methods to enhance expression and clarify understanding
- within a sensitive environment, participants could manage anxiety in order to participate;
- fundamentally, there is a need to 'keep it simple'.

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